



UPCOMING EVENTS, TRAININGS, ACTIVITIES



Assistive Technology Resource Fair

Tuesday
February 12, 2019
6:00–8:30 pm
UC Davis MIND
Institute, Auditorium
2825 50th St.
Sacramento, CA

CENTER FOR EXCELLENCE IN **DEVELOPMENTAL DISABILITIES**

Annual Tools for Inclusion Resource Fair

Assistive Technology can provide access and opportunity for people with all disabilities. This resource fair will highlight ways that AT can be used to allow full access and inclusion for all!

The Resource Fair will include:

- Panel discussion from self-advocates on using AT.
- Resource tables: state agencies and organizations that support individuals with disabilities.
- Demonstrations and mini-workshops on a variety of assistive technology devices and strategies.
- Networking opportunities, and more.

This fair is brought to you by our community partners:



UCDAVIS
STUDENT DISABILITY CENTER

Parking:

Parking in Lot 25 is \$6. Parking on the street is free.

Sponsored by

The UC Davis CEDD Assistive
Technology Consortium

UCDAVIS
MIND INSTITUTE



WarmLine Family Resource Center

Presents:

What Should I Know About 504 Plans?

Some kids with learning and attention issues don't need (or are not eligible) for special education.

Depending on their challenges, they may be able to get help through a 504 plan.

504 plans are designed to help kids with disabilities learn alongside their peers. They do this by removing barriers to learning.

504 plans aren't the same as IEPs. They're each covered by different laws and work in different ways. If your child has an IEP, please call WarmLine to ask if this training would benefit you.

Tuesday, March 26 — 6 p.m. to 8 p.m.

Kids First

124 Main Street, Roseville

This training is FREE, but registration is required.

Please register at <http://bit.ly/2AHDPaT>.

Call 916-455-9500/844-455-9517 for more information.

Each family will receive a gas card and WarmLine tote bag.



DAD-Vocates

(Formally Trailblazers Fathers' Forum)

Teaching dads the skills to advocate for services for their children with disabilities. We learn from each other about Special Education, ALTA California Regional Center, adult services, transitions, and other valuable topics dads need to know. This is a priceless opportunity for dads to learn!



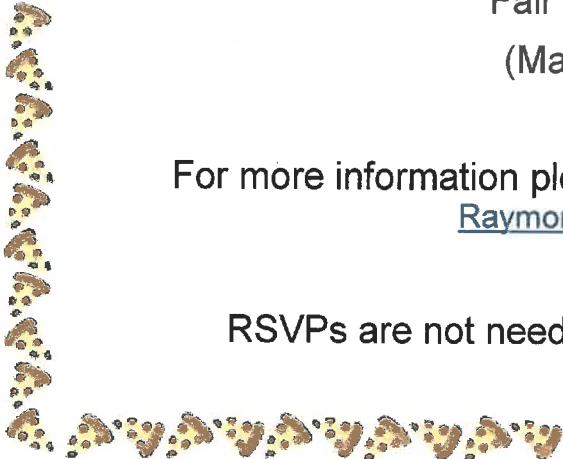
We meet at 7pm on the LAST Tuesday of the month.

Location: Round Table Pizza

8822 Madison Ave

Fair Oaks CA 95628

(Madison & Hazel)



For more information please contact Raymond Hampson at
Raymond8690@yahoo.com

RSVPs are not needed. Drop-ins are very welcome.

Brian, Kathy@SCDD

From: Aimee Myers <amyers@scoe.net>
Sent: Thursday, January 24, 2019 7:38 AM
To: Tania Salazar; Laura Lysrup; Kathleen Larson; Robin Ryan; coachholm7@gmail.com; erika.chilcott@gmail.com; Linda Clinton; Brian_Kathy@SCDD; EunMi Cho; mhoisington@altaregional.org; jreven2010@gmail.com; vperez@altaregional.org; rositalinda@citlink.net; msmargo@softcom.net; Meladee McCarty; lyssie_missie@yahoo.com; Jessica Markov; Jennifer Adaya; cid@warmlinefrc.org; turnerbrownwedding@gmail.com; Kathy Johnson; Sandy Graham; esmecastro3@aol.com; Rhodd@arcohe.net; Tamara Allen; Maggie Blumberg
Subject: Fw: WarmLine Special Education Newsletter ~ January 2019

From: WarmLine Parent Training & Information Center <kelly@warmlinefrc.ccsend.com> on behalf of WarmLine Parent Training & Information Center <warmline@warmlinefrc.org>
Sent: Wednesday, January 23, 2019 5:59 PM
To: Aimee Myers
Subject: WarmLine Special Education Newsletter ~ January 2019

Having trouble viewing this email? [Click here](#)



WarmLine Special Education Newsletter

January 2019

What Should I Know About 504 Plans?

Some kids with learning and attention issues don't need (or are not eligible) for special education. Come learn how 504 plans differ from IEPs at 6 p.m. on March 26, 2019. [Register Now](#) [Download Flyer](#)



Special Education Clinics & Workshops by WarmLine

Click on the blue event names below for more information and to register online.

January		
Ayuda! Mi hijo tiene problemas de comportamiento en la escuela! (Spanish <i>only</i>)	Wednesday, Jan. 30	Woodland
February		
Understanding Special Education	Saturday, Feb. 2	Chico
Turning 3 Years Old: The Transition to Preschool	Thursday, Feb. 28	Sacramento
March		
Vamos a Organizarnos (Spanish <i>only</i>)	Tuesday, March 12	Sacramento
Understanding Special Education	Tuesday, March 20	Wilton Rancheria
What Should I Know About 504 Plans?	Tuesday, March 26	Roseville

Just for Youth & Young Adults

Print: [2019 Goals Calendar for Tween with Executive Functioning Issues](#) from Understood.org

You bring the creativity and the Central Library will provide the supplies for a "Random Acts of Kindness" craft/service project at 11 a.m. on Feb. 5. [Learn More](#)

Resource: [Accommodations for Test Takers with Disabilities](#) from the College Board

The California Committee on Employment of People with Disabilities has extended the Youth Leadership Forum for Students with Disabilities application deadline until Feb. 3. [Learn More](#)

For Your Information...

Read: [6 Things I Wish I'd Known Sooner About My Son's Anxiety](#) from Understood.org

Resource: [Assistive Technology 101](#) from the Center on Technology and Disability

Resource: [The Power of Play](#) excerpted from Kidspot.com and Zero to Three

Read: [It's A Kids Job](#) about how playing helps kids learn and grow from the National Institutes of Health

[Paving the Way: Parent Tips for Supporting Success in High School and Beyond](#) from PACER.org

Resource: [Accommodations: What They Are And How They Work](#) from Understood.org



Types of Assessments

Children who have disabilities and special health care needs are often subject to several types of assessments meant to better identify their area(s) of need. In this occasional series, WarmLine shares different assessments, what they look for and how that information is used to support the child. This month: [Comparing Psychological vs. Psychoeducational vs. Neuropsychological Evaluations.](#)

Did You Know?

WarmLine is a federally-funded Parent Training and Information Center and coaches parents navigating the special education process. Use our [Contact Form](#) or call us at (916) 455-9500 for a one-on-one consultation.



Funding for WarmLine is provided by the U.S. Department of Education, Office of Special Education Programs as a Parent Training and Information (PTI) Center.



WRAP®

Wellness Recovery Action Plan A supportive, interactive, fun 8-week workshop

Registration is required. Participants must commit to attending all eight sessions as each class builds on the next.

Wellness Recovery Action Plan, WRAP, is a highly effective program, created by Mary Ellen Copeland, that enables individuals to regain control of their lives. It is a strengths-based self-help tool that empowers you to identify warning signs and events that may lead to difficulties.

During WRAP sessions, you will also explore wellness tools that can help you to overcome such challenges.

Sessions offered
year round.

For more
information, call
Maksim Tsymbal
(916) 366-4668

ASSISTING YOU ON THE ROAD TO RECOVERY



Workshops at:
NorCal MHA
720 Howe Ave Suite 102
Sacramento, CA 95825

Create a set of powerful personalized tools, plans
and goals uniquely designed to improve
your quality of life

Hope Personal Responsibility Education Self Advocacy Support

This program is funded by the Sacramento County Division of Behavioral Health Services through the voter approved Proposition 63, Mental Health Services Act (MHSA).



WRAP[®]

2019 Wellness Recovery Action Plan A supportive, interactive, fun 8-week workshop

January, February, March
Thursdays from 1 to 3:00

January 24th
January 31st
February 7th
February 14th
February 21st
February 28th
March 7th
March 14th

Norcal MHA
720 Howe Ave
Suite 102
Sacramento,
CA 95825

April, May, June
Thursdays from 1 to 3:00

April 18th
April 25th
May 2nd
May 9th
May 16th
May 23rd
May 30th
June 6th

July, August
Thursdays from 1 to 3:00

July 11th
July 18th
July 25th
August 1st
August 8th
August 15th
August 22nd
August 29th

To Register
call Karly
Mathews or
Jensen Bosio
(916)366-4668

September, October, November
Thursdays from 1 to 3:00

September 26th
October 3rd
October 10th
October 17th
October 24th
October 31st
November 7th
November 14th

Create a set of powerful personalized tools, plans
and goals uniquely designed to improve
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Hope Personal Responsibility Education Self Advocacy Support

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Self-Determination Program information

WHAT IS SELF-DETERMINATION

Adults with disabilities or families of children with disabilities, with the support of family, friends, and professionals whom they trust, taking charge of their own futures by gaining control over the services, supports and resources that they need. You decide what services you'd like and who should provide them. Additionally, Self-Determination is voluntary.

How does it work? You are given an INDIVIDUALIZED BUDGET

The law says that individualized budgets must be determined fairly and that everyone must be treated the same way. The law also says that Self-Determination will be phased-in over three years. The amount of money spent on services for the previous 12 months will be the amount of money you get for your Individualized Budget. The budget will be good for one year and it can be adjusted for reasons such as a change in circumstances or unmet needs. A new Individual Program Planning (IPP) will be needed to reflect the change and document any budget adjustment.

A person-centered plan is written with the help of a FACILITATOR

A Facilitator is someone you hire to help you. Hiring a facilitator is *optional*. You pay for the Facilitator out of your budget, but you can get a facilitator for free if you have a family member or friend willing to take on that task – but they have to be trained and qualified. Your Facilitator helps you find the services and support you need. Some of your supports will be free and come from your family, friends, and other people you know. Some of your services will be paid for out of your budget. Your Facilitator helps you find and hire the right people to support you and to decide how much they should be paid. The Facilitator makes sure everyone you hire is qualified and that you don't spend more money than you have in your budget.

The money in your budget is sent to a FINANCIAL MANAGEMENT SERVICE

YOU CHOOSE THE FMS. When your plan is finished and your services and supports are in place, the regional center sends the money in your budget to a Financial Management Service, or FMS. The money is given to the FMS to protect you from having to pay taxes and from being sued. The FMS takes care of paying taxes and insurance and makes sure the people working for you don't have criminal records. The FMS does not tell you how to spend your money. The FMS keeps your money safe and pays the people you hire. The FMS keeps track of how much you spend.

When can people get Self-Determination?

Self-Determination will not be available until California gets a **FEDERAL WAIVER**

Getting a federal waiver allows the state to get back some of the money spent on Self-Determination services. The state has already applied once. Another version of the waiver will be submitted soon. After the waiver is approved regulations will be written.

What can people do now?

Let your service coordinator know that you want Self-Determination and have it put in your IPP. The Department of Developmental Disabilities (DDS) is responsible for applying for the federal waiver. You can receive updates from www.dds.ca.gov/sdp/ and actively participate in the Self-Determination Advisory Committee meetings at your regional center. In the near future, it is expected that regional centers will hold "pre-enrollment information meetings". *Individuals interested in participating in the Self-Determination Program will be required to attend these meetings.* Afterwards, individuals may add their name to a list of those interested in Self-Determination, which will be sent to DDS. DDS will then randomly select who shall participate in Self-Determination during the roll out of the program for the first three years.

¿QUÉ ES LA AUTODETERMINACIÓN?

Los adultos con discapacidades o familias de niños con discapacidades, con el apoyo de familiares, amigos y profesionales en quienes confían, tomando las riendas de su propio futuro por obtener el control de los servicios, apoyos y recursos que necesitan. Usted decide qué servicios le gustaría y que deben proporcionarlos. Además, la autodeterminación es voluntaria.

¿Cómo funciona? Se le da un **PRESUPUESTO PERSONALIZADO**

La ley dice que los presupuestos individualizados deben ser determinadas de manera justa y que todos deben ser tratados de la misma manera. La ley también indica que la autodeterminación será gradualmente implementada en los próximos tres años. Durante ese período de tiempo el centro regional verá en todos los servicios que actualmente recibe, se sumara lo que se ha gastado, y el total será el monto de su presupuesto individualizado – usted obtendrá la misma cantidad de dinero que se gastó el año anterior. El presupuesto es válido por un año y puede ajustarlo por razones como un cambio en las circunstancias o necesidades no satisfechas. Un Plan de la Programa Individualizada (IPP) será necesario para reflejar el cambio y documentar cualquier ajuste presupuestario.

• **Un plan centrado en la persona está escrito con la ayuda de un FACILITADOR**

Un facilitador es alguien que usted contrate para ayudarlo. La contratación de un facilitador es *opcional*. Usted paga por el Facilitador de su presupuesto, pero usted puede conseguir un facilitador gratis si usted tiene un familiar o amigo dispuesto a asumir esa tarea - pero tienen que ser entrenados y calificados. Su facilitador ayuda a encontrar los servicios y apoyos que necesita. Algunos de sus soportes serán gratis de costo y provienen de su familia, amigos y otras personas que conoce. Algunos de sus servicios se abonarán a través de su presupuesto. Su facilitador ayuda a encontrar y contratar a las personas adecuadas para apoyar a usted y decida cuánto debe ser pagado. El facilitador se asegura que todas las personas que usted contrate están calificadas y que no gaste más dinero del que tiene en su presupuesto.

• **El dinero en su presupuesto es enviado a un SERVICIO DE GESTIÓN FISCAL**

(FMS, las siglas en ingles) **USTED ELIGE EL FMS**. Cuando su plan está terminado y sus servicios y apoyos están en su lugar, el centro regional envía el dinero en su presupuesto a un Servicio de Gestión Fiscal, o FMS. El dinero es entregado a la FMS para protegerse de tener que pagar impuestos y de ser demandado. El FMS se encarga de pagar los impuestos y el seguro y se asegura de la gente que trabaja para usted no tengan antecedentes penales. El FMS no le dice cómo gastar su dinero. El FMS mantiene su dinero seguro y paga la gente que usted emplea. El FMS mantiene un registro de lo que gasta.

¿Cuándo la gente puede conseguir la autodeterminación?

Autodeterminación no estará disponible hasta que California consiga un **RENUNCIA FEDERAL**. Conseguir una renuncia federal permite al estado recuperar parte del dinero gastado en servicios de autodeterminación. El estado ya ha aplicado. Otra versión de la renuncia se presentará pronto.

¿Qué puede hacer la gente ahora?

Comuníquese con su coordinador de servicios y deje le saber que usted quiere la autodeterminación y lo han puesto en su IPP. El Departamento de Servicios de Desarrollo (DDS) es responsable de la aplicación de la renuncia federal. Recibe actualizaciones de www.dds.ca.gov/sdp/ y participar activamente en las juntas del Comité Asesor de Autodeterminación a su centro regional.

En el próximo futuro, se espera que los centros regionales llevarán a cabo "juntas de información antes de inscripción". Las personas interesadas en participar en Autodeterminación necesitan asistir a estas juntas. Posteriormente, los individuos pueden añadir su nombre a una lista de los interesados en la autodeterminación, la cual será enviada al DDS. DDS seleccionará al azar quien participará en la autodeterminación durante el despliegue de la programa por los tres primeros años.

Self-Determination Program Services by Category

Budget Category	Services
Living Arrangement	<ul style="list-style-type: none"> √ Community Living Supports √ Financial Management Services √ Homemaker √ Housing Access Supports √ Live-In Caregiver √ Respite Services
Employment and Community Participation	<ul style="list-style-type: none"> √ Community Integration Supports √ Employment Supports √ Independent Facilitator √ Individual Training and Education √ Non-Medical Transportation √ Participant-Directed Goods and Services √ Prevocational Supports √ Technology √ Transition/Set Up and Expenses
Health and Safety	<ul style="list-style-type: none"> √ Acupuncture Services √ Behavioral Intervention Services √ Chiropractic Services √ Communication Support √ Crisis Intervention and Support √ Dental Services √ Environmental Accessibility Adaptations √ Family/Consumer Training √ Family Support Services √ Home Health Aide √ Lenses and Frames √ Massage Therapy √ Nutritional Consultation √ Occupational Therapy √ Optometric/Optician Services √ Personal Emergency Response Systems √ Physical Therapy √ Psychology Services √ Skilled Nursing √ Specialized Medical Equipment and Supplies √ Speech, Hearing and Language Services √ Training and Counseling Services for Unpaid Caregivers √ Vehicle Modifications and Adaptations

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Other articles of
interest

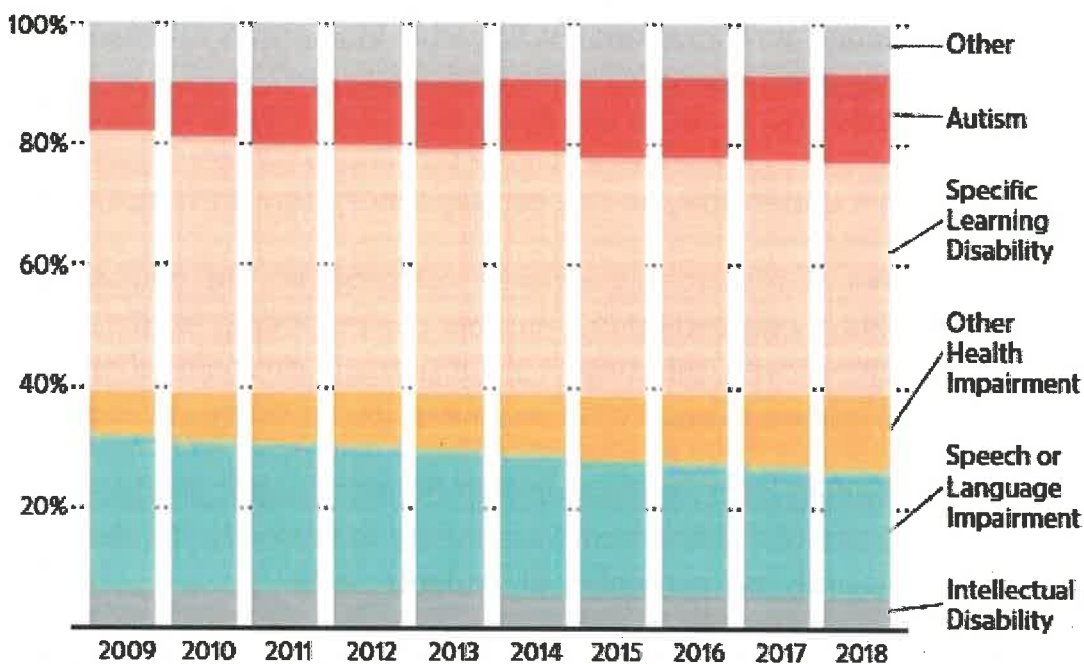
Shared from the 1/20/2019 The Sacramento Bee eEdition

Special education enrollment in California has surged

BY MICHAEL FINCH II mfinch@sacbee.com

California special education enrollment

Over the last decade, the share of the students enrolled in special education with an autism diagnosis was among the fastest growing subgroups.



Note: Years are school years; 2009, for example is school year 2008-2009

Sources: California Department of Education; Bee analysis

MICHAEL FINCH II mfinch@sacbee.com



first, but when they were 14 months old, doctors sensed they might have a condition.

Neda Raheem is a 34-year-old mother of twin boys and a physician assistant. Her boys seemed normal and healthy at

"They didn't have any problems hearing but a lot of problems with movement," Raheem said. "They didn't like to be in a swing and they didn't like their hands, especially, to be touched."

The boys were diagnosed with autism and cerebral palsy. Three months into preschool, the family moved from West Sacramento to Elk Grove in part because the schools offer more options for special education students.

It's the type of decision parents across the Central Valley are facing with increasing regularity, as autism diagnoses soar and parents seek classrooms with better options for their children.

Special education enrollment has surged in the last decade, with more than 96,000 students pouring into school districts across the state, according to data from the California Department of Education.

One of the drivers has been a marked increase in students with autism and other behavioral delays, a Bee analysis shows. At the same time, the number of students with other disabilities grew modestly or decreased between the 2009 and 2018 school years.

Although the trend is undeniable, no one can say exactly why it's happening.

The answer, according to researchers, social service providers and education administrators could be wrapped up in a number of overlapping factors. Outpacing population growth, the surge has put pressure on some school district budgets and administrative support systems in the Central Valley and beyond.

State and federal funding have not kept up with the shift in special education enrollment, forcing school districts from Sacramento to Fresno to dig deeper into their general funds to pay as the number of students swells.

"If you look at the population of kids that are classified as special ed, that number hasn't really changed," said Erika Hoffman, a lobbyist for the California School Boards Association. "It's the concentration of students within that number and that's where it's affected a lot of schools because services for students with autism can be very expensive."

The increased prevalence of autism has been a medical mystery for years.

Awareness has grown, experts say. Teachers are trained to recognize the disorder. And in 2013, the medical definition of autism was changed, grouping a number of

conditions like Asperger's syndrome and pervasive development disorder under the umbrella of autism.

Recent estimates from the Centers for Disease Control and Prevention said the prevalence of autism spectrum disorder jumped 16 percent between 2012 and 2014. Although the medical and education definitions are not the same, California schools saw an 18 percent increase in autism enrollment for the same period.

But organizations like the MIND Institute at UC Davis have been working to bring the two definitions closer together by training teachers and other professionals to identify the symptoms.

"The increase isn't just in California but it is nationwide, probably worldwide," said Aubyn Stahmer, who oversees community treatment research at the MIND Institute. "The diagnostic definitions have broadened a little bit and that explains some of it and awareness has really increased quite a bit."

FUNDING CHALLENGE

In requiring school districts to offer special education, the federal government agreed to pay about 40 percent of the per student cost. Hoffman said the reality has often been much less, between 12 and 15 percent of the cost.

The state chips in for 30 percent and school districts are on the hook for the rest.

In his first budget, Gov. Gavin Newsom acknowledged the shortcomings in special education funding and directed \$576 million to schools — about one-third of which is a onetime payment, according to a released spending plan. It's unclear, however, if the proposed budget for special education would be consequential in closing the funding gap.

In the Fresno Unified School District, special education accounts for about 14 percent of its budget. In the last decade, state education data shows enrollment jumped by 6 percent but the share of students with autism climbed nearly three-fold.

Susan Kalpakoff, Fresno Unified's special education program manager, said students are not necessarily flocking to the district from other places but a lot of them are younger than 5 years old.

"Are more resources required or needed for our students with autism? The answer is yes," Kalpakoff said. "When we look at all the eligibilities of students, there are

groups of (disabilities) —autism being one — that require more specialized understanding and training.”

Kalpakoff sees an upside in the increase. If there are more students being diagnosed, she said it shows the school system must be doing a good job identifying children in need.

Officials with the Elk Grove Unified School District, the fifth largest in the state, say they’ve seen more parents arrive with 3- to 5-year-old children who have already been diagnosed in another school district. “Our budget is impacted by the increase in 3- and 4-year-olds because there is no funding for that early education age-group, so we have to look at re-prioritizing programs,” said district spokeswoman Xanthi Pinkerton.

“We are having to do more to recruit teachers, and in some cases, we are helping to cover the cost of credentialing current staff interested in becoming special education teachers.”

Parents will move if a district offers the right services and some cater to those students’ needs better than others, said Dave Gordon, superintendent of the Sacramento County Office of Education.

Research has shown early intervention is more likely to improve a child’s outcomes, so it’s likely parents will gravitate to those places, Gordon said. “In Elk Grove, I know they’ve set up a very broad-based set of services for preschool age (students), which is not as common.”

While Raheem’s family moved into Elk Grove for help from the schools, her twins’ conditions are more complicated than most. When the twins were diagnosed, the doctor told Raheem their motor functions were lagging, further holding them back. They were also diagnosed with cerebral palsy.

Even with the abundant programs, Raheem disagreed with some of the school’s treatment plans. She placed the boys in full-time behavioral therapy late last year to better address the needs of the overlapping diagnoses.

“I could not get what I felt my kids needed the most,” Raheem said, “so I had to make that decision and take them out of the public school system.”

See this article in the e-Edition [Here](#)

ASSISTIVE TECHNOLOGY 101

Get informed about assistive technology for your child.



Authored by:
Jacqueline Hess, FHI 360
Ana-Maria Gutierrez, FHI 360

The U.S. Department of Education established the **Center on Technology and Disability (CTD)** to provide a wide range of assistive technology resources for families, teachers, service providers, advocates, researchers, teacher training programs, disability organizations, and vendors.

The CTD website – www.ctdinstitute.org – has a resource library with more than 1,000 assistive technology-related materials; a webinar center with an active schedule of informational presentations, and extensive archive; and a learning center for those who want structured, in-depth modules.

The views expressed herein do not necessarily represent the positions or policies of the Department of Education. No official endorsement by the U.S. Department of Education of any product, commodity, service or enterprise mentioned in this publication is intended or should be inferred. Suggested citation for reprint should be: Assistive Technology 101 (2018), Center on Technology and Disability.



The Center on Technology and Disability is funded by the U.S. Department of Education, Office of Special Education Programs (OSEP) under award #H327F130003 – 13A.

Why Learn about Assistive Technology?

Assistive technology (AT) makes it possible for individuals with disabilities to take part in life's activities, at home, school, work, and in the community. It strengthens developmental, functional, and learning skills. It can substitute for abilities that a person may not be able to develop. For instance, a person may not have use of her voice, but AT can allow her to communicate her thoughts, wants, and needs. No one is too young or too old to benefit from AT.

What Is Assistive Technology?

Assistive technology includes a wide range of tools, from a simple, low-tech device such as a magnifying glass, to a complex, high-tech device, such as a computerized communication system. AT products can be made by hand, purchased off the shelf, or adapted from an existing product.

Assistive technology services help individuals acquire and use AT devices. They include, but are not limited to: assessment of an individual's need for specific AT items, "trialing" of potential devices, training for all involved, maintenance of devices, and evaluation of the individual's experience with selected items.

Sometimes an item that is not thought of as assistive technology will fall into the AT category if it permits someone to accomplish a task that he could not successfully complete otherwise. An example would be the use of a calculator in school. For some students, a calculator may provide an easier, faster way of solving a math problem. For students with certain physical and/or intellectual disabilities, the calculator may be essential to their ability to solve the same problem. For those students, the calculator becomes assistive technology and its use may be approved in an Individualized Education Program (IEP).



Meeting Challenges with Assistive Technology

Infants, toddlers, children, and young adults may use assistive technology to help them move, communicate, learn, work, and socialize. In most cases, the AT devices that a person uses will change over time, as s/he grows and develops physically, intellectually, and emotionally. This is particularly the case with young children and youth. AT appropriate for a 3-year old will rarely be suitable for a 7-year old or a 12-year old. It's important, therefore, to regularly evaluate a child's needs and experiences with his or her devices, services, and accommodations.

In thinking about the potential value of AT to a particular child, remember that not all disabilities are identified formally. Many children have “invisible” disabilities which may or may not have been diagnosed by a doctor or service provider. Yet these can have a powerful impact on a child's ability to develop, learn, and socialize with peers and adults. Some of the disabilities that often fall into the “invisible” category are learning disabilities, print disabilities, auditory processing disorders, and emotional/behavioral control.

Children with both diagnosed and undiagnosed disabilities, whether visible or invisible, can benefit from appropriate assistive technology. It is more difficult, however to acquire AT through public agencies, including school systems, without a diagnosis. For children age 0-3, a diagnosis will, in most cases, trigger the development of a Family Individualized Service Program (IFSP); for children and youth age 4-22, the development of an Individualized Education Program (IEP). Federal law—the Individuals with Disabilities Education Act (IDEA)—requires that the IEP process include consideration of a child's need for accommodations, including assistive technology. (Please note that not all accommodations are AT. Non-AT accommodations may include additional time when taking tests, the ability to access a resource room for quiet time, the assignment of a study buddy, or the assignment of easier, modified homework.)



Choosing the Right Assistive Technology for a Child

To determine the assistive technology needs of a child, an AT assessment should be conducted. The assessment can be conducted by the child's school, an independent agency, or an individual consultant. The assessment should take place in the child's customary environments; most often that will be at home or at school.

It is important that the assessment address the child's strengths as well as his or her weaknesses. The perspectives of teachers, parents and service providers are important, as well as that of the child. The discussion should include the ways in which the child communicates, what he or she likes and dislikes, and what kind of strategies and interventions might be helpful. Consider how a child's need for AT might change depending on the environment, for example, in the classroom, on the playground, at a friend's house, or in a public place such as a shopping mall or library. That type of input will provide clues as to what technology might work and how well the child will respond to it.

If an AT assessment is conducted as part of a student's IEP process and it is determined that one or more AT devices and/or software would help achieve the goals identified in the IEP, then the school system is required by law to provide the AT. The school has flexibility in choosing among products that meet the student's needs and the products may be acquired from the school system's equipment re-use inventory, but it must provide the features identified in the AT assessment.

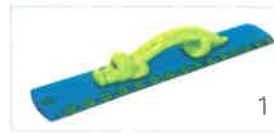
Examples of Assistive Technology to Consider

Examples of assistive technology that support development, communication, learning, play, and independent living include the following:

- Computer apps for tablets and phones can help infants and toddlers with developmental delays learn cause and effect and facial expressions. Used by the child with an adult, such apps provide the type of early intervention that can help narrow or even eliminate a young child's delays.
- Many toys can be easily adapted or purchased off the shelf to be accessible by children with fine or gross motor weaknesses. These include puzzles with knobs, motion toys with big button switches, push or ride-on toys with wheels wrapped in Velcro for stability, and game pieces with handles.



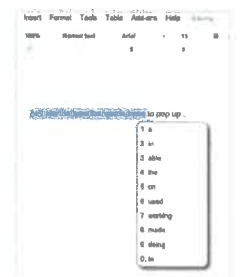
- Learning materials can be similarly adapted. Adding a handle to a ruler, page “fluffers” to books, or 3-D stickers to blocks can help a child independently participate in classroom activities. Timers, task reminders, visual cues, and “first-this-then-that” software programs help students make transitions between activities. Audio versions of books are available through a number of sources, including Bookshare and community and school libraries.



- For students with learning disabilities, there are a wide range of idea organizers for help in understanding lessons and text content. They also help a student organize his or her thoughts and written assignments. A teacher might allow a student with disabilities to submit an audio or visual report instead of a written essay, using the audio recording or picture-taking functions on their cell phone or tablet computer.



- Other AT tools that are widely available through computers and mobile devices include voice recognition, screen enlargement, and font controls. These are no longer high-price accessibility tools available through specialty catalogues, but are routinely built in to widely available consumer devices. With minimum effort, they can be easily customized to each individual's needs.

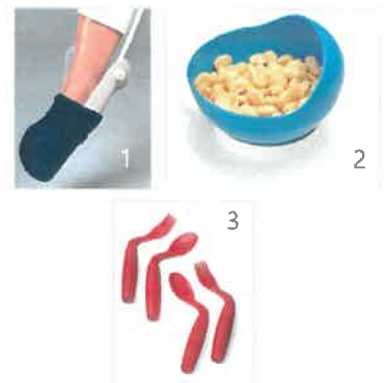


- AT items that support mobility and independence include hand-held GPS (global positioning system) devices and apps that help people with visual impairments navigate city streets and use public transportation.

- Assistive technology can also help children, youth, and adults participate in recreational and community activities. Increasingly, communities are investing in accessible playgrounds so that all children can play safely. Adapted equipment allows youth to play such sports as baseball, basketball, and tennis. Accessibly designed movie theaters provide closed captioning and audio description for moviegoers with hearing and visual difficulties.



- Devices to assist a person with “activities of daily living (ADLs)”, such as cooking, dressing, and grooming, help individuals of all ages. A medication dispenser with an alarm can be set to remind a child or adult to take daily medication. Talking clocks, scales, and measuring cups help those with visual impairments. Dressing sticks and long-handled brushes encourage independence, as do reaching tools, color-coded labels, and a large variety of mobile apps that provide visual cues to the steps in an activity.



Learning More about Assistive Technology

You don't have to become a “techie” to help an infant, child, young adult, or adult with disabilities access and use AT. Through websites, YouTube videos, and social media networks, it's easier than ever to not only learn AT basics, but to stay on top of new technology products as they become available. Whether you're someone with a disability, a family member, teacher, service provider, or any concerned individual, you simply need a willingness to invest time to learn and a belief that AT can make the seemingly impossible, possible. There are many organizations that provide AT information and training to consumers, families, and educators, such as parent training and Information centers, state assistive technology programs, disability-specific organizations, and rehabilitation centers. If possible, you should visit an AT center that provides demonstrations and workshops and that may loan devices for users to try.

Please return to the **Center on Technology and Disability's website** regularly to look for new resources. You can also sign up to receive an announcement of upcoming webinars and newly released guides, videos, infographics, and fact sheets. We look forward to seeing you online!

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Center on Technology and Disability

www.CTDinstitute.org

"Assistive and Instructional Technology Supporting Learners with Disabilities"

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WASHINGTON, DC 20009
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ABLE Act

Achieving a Better Life Experience

How to save money and keep your benefits



Introduction

In 2014, the United States Congress passed a law called the ABLE Act. It stands for Achieving a Better Life Experience. The purpose of this law is to create a way for people with disabilities to be able to save money easily without losing their public benefits.

In this booklet you will learn the basic information about the ABLE Act. This is an overview only; it is not a comprehensive guide to ABLE accounts. You will find on-line resources in the back that will have more detailed, current information.

If there are words in this booklet that you don't understand, please go to the Glossary on page 15 for a simple definition of the word or term as it relates to the ABLE Act.

All of the amounts of money discussed in this booklet may change in the future. Go to the California State Treasurer's website for the most current information.¹

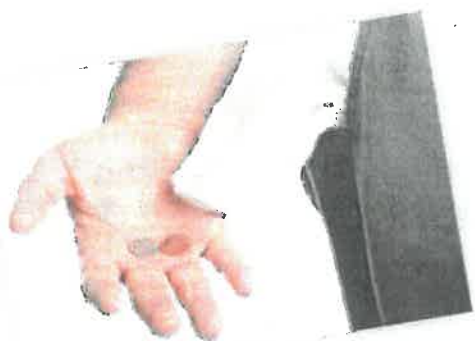
The information in this booklet is accurate as of December 2018. Revisions will be made as new information is available.

Right now

Some people living with disabilities and their families rely on a variety of public benefits provided by state and federal governments to make ends meet. Public benefits include Supplemental Security Income (SSI), Medicaid, CalFresh, Section 8 and other state programs. These programs provide important support for people with disabilities but often do not allow individuals to save more than a total of \$2,000, or earn more than \$680 a month.

This means that people who have these benefits cannot save money so they stay poor. Instead, people are forced to "spend down" any extra money they have leading to unnecessary purchases of things they don't need or want.

¹ www.treasurer.ca.gov/able



Before the ABLE act was passed, the only method available for saving money without impacting benefits was to set up a special needs trust. Such trusts are useful, but they are expensive, complicated and do not give the beneficiary any control of the money.

Huge improvement

The ABLE Act gives eligible people a simple way to save without the risk of losing their public benefits. It also permits them to grow their savings through investments without being taxed on that growth.

These accounts are also called 529(A) accounts. They are similar to College Savings Plans called 529 plans. Earnings and distributions are not taxed as long as they are used for qualified expenses.²

Within some limits, a person can save money and still receive their full benefits!

In addition to being able to save money, the beneficiary owns the account thus giving them control over their own money.



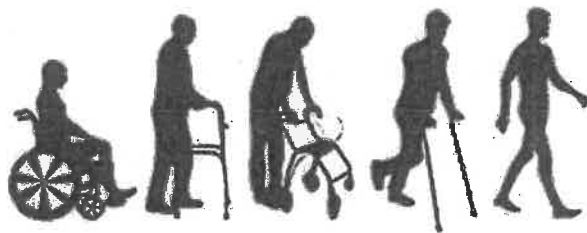
² We will discuss qualified expenses later in the handbook.

Eligibility

To be eligible a person must be disabled before the age of 26. You can establish an account if you are older than that, as long as your disability started before age 26.

You are automatically eligible if you receive Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) and meet the age requirement.

You can also be made eligible if you have a disability with “marked and severe” functional limitations that will last at least one year. This will require a physician’s certification.



Establishing an account

ABLE account administration will be set up by each state. In California, the CalABLE board, under the auspices of the State Treasurer, is appointed to manage the ABLE account system.

Every person may have only one account at any given time. The account may be set up in any state. However, some states may limit their accounts to their residents only.

More than 40 states have already started permitting people to set up ABLE accounts with over 15,000 accounts opened nation-wide. CalABLE went live in December 2018.

Contributions

Anyone, including the beneficiary, can make contributions to the ABLE account. These are made after taxes are paid. There is no federal tax benefit for most contributors.³ Beneficiaries may be able to claim a tax credit on contributions as described later in this booklet.



\$15,000⁴ a year may be contributed to an ABLE account. This is also known as the Annual Limit. However a beneficiary who works may be able to contribute more as described on the next page.

The maximum amount you can have in an account at any time is decided by the state. California's limit will be \$529,000⁵.

Working Beneficiaries

If a beneficiary works, they may contribute more to their account than the Annual Limit of \$15,000. They can contribute either the amount of their gross yearly income or \$12,140, whichever is less. There are a couple of rules about this:

1. Only the beneficiary may make this extra contribution out of their earnings.
2. There must be no employer-based retirement account set up for the beneficiary, even if only the employer contributes to it.

Regular annual contribution \$15,000
Contribution from earnings + \$12,140
Total annual amount = \$27,140

³ Some states have tax benefits for contributors. Tax benefits are based on the state of residence of the contributor, not where the ABLE account is established.

⁴ This amount may be adjusted in the future.

⁵ This amount may be adjusted in the future.

Rollovers

529 College Savings Plans

If the beneficiary or a family member has a 529 college savings account, that money can be rolled over into the beneficiary's ABLE account. This amount counts towards the \$15,000 annual contribution limit.

Other 529(A) ABLE Accounts

You can rollover funds from a 529(A) into another 529(A) from one sibling to another eligible sibling. This rollover does not count towards the \$15,000 annual contribution limit.

Over the limit

If contributions push the account over the annual limit, contributions will be returned to the contributor. The last money put into the account will be the first money returned. The beneficiary will be notified when this happens.



Saver's Credit

When a low or moderate income beneficiary contributes to their own account, they may be able to claim a tax credit, called the Saver's Credit.

To be eligible for this credit, the beneficiary must:

- Not be a full time student
- Not be a dependent
- Contribute to own ABLE account
- Owe taxes
- As a single person, earn no more than \$32,000 or, as a married couple, earn no more than \$64,000 adjusted gross income per year.

This tax credit is a percentage of the amount the beneficiary contributed to their own ABLE account. That percentage starts at 50% for the lowest income levels and reduces to 10% for those closer to the high income threshold. The maximum credit is \$2000. The amount of the credit reduces the amount of taxes owed by the beneficiary. If the credit is greater than the amount of taxes owed, there is no refund of the remaining balance.

Using your money

You can use ABLE funds to pay for Qualified Disability Expenses (QDE). QDEs are expenses that are related to one's disability, are for the benefit of the beneficiary and will permit that person to maintain or improve **health, independence or quality of life**.

The ABLE Act is clear that the requirements on what a QDE is should be applied loosely meaning that most types of expenses should be allowed as QDEs.

You should keep good records of how you use your ABLE funds. It is suggested that you keep every receipt and have a log with a short description of every purchase and how it is a QDE. This will protect you if the Internal Revenue Service audits your ABLE account.

- ABLE account money may be used to pay for basic living expenses
- Expenses do not have to be medically necessary
- Expenses are still qualified even if there is some benefit to others; however expenses that are only for the benefit of another, such as gifts or donations, are not allowable.
- Money used from an ABLE account for QDEs is not taxable

QDEs include.....

- Education
- Housing
- Transportation
- Employment supports and training
- Assistive technology
- Personal supports
- Health
- Financial management
- Legal assistance
- Oversight/monitoring
- Basic living expenses
- Funeral/burial⁶

Non-qualified expenses will be taxed and have an additional penalty of 10% of the amount taken out. They could also impact your eligibility for MediCal or other public benefits.

Investing your money

Money in an ABLE account will be invested by the account managers contracted by the ABLE Board. In addition to contributions you make, this is how your account can grow. If your account grows through investments, that money is not taxed.

The other side of investment is that there is a risk that your account will lose money. Usually investments do some of both. One month you will see your

⁶ For a more extensive list, go to the end of this booklet.

account increase while another month it might decrease. Over time usually money that is invested increases more than it decreases.

When you have an account, you will be offered choices in how you want your money invested. Some options will have the possibility of a lot of growth; these options also have a higher risk of losing money. Other options will have a low risk of losing money but these also will have lower growth.

How you invest your ABLE account will be an important decision. We cannot cover all of the information you need to know about investing here. Be sure to ask the person who is helping you establish your account what each investment option is so you can decide what you are comfortable with.

Account management

In California, the account manager has set up various investment options for ABLE accounts. If you have your account here, you will be able to select which one suits you for the growth and risk you want. You can change your investment option up to twice a year.

If you choose to set up your account in a different state, you will have to learn the rules for that state's ABLE accounts.

The ABLE account managers will report information about your account to Social Security every month.



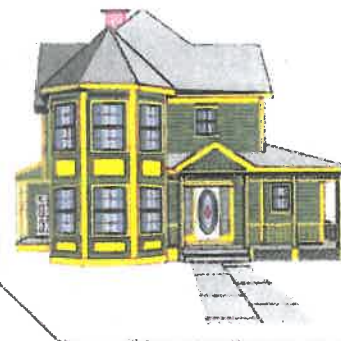
ABLE and Social Security

Probably the best feature of ABLE accounts is that account funds will not impact your public benefits. The only public benefit that may be impacted is your SSI cash benefit.

In the case of SSI, you can have up to \$100,000 in your account and still get your full SSI check each month. Once you pass that amount of money in your ABLE account, your SSI cash benefit will stop, but you will still remain eligible. If your account goes below \$100,000, then you will start getting your SSI checks again.

A note on housing

SSI benefits can be affected if you use ABLE funds for any housing expenses and don't spend the money right away. To avoid any impact to your SSI benefits, be sure to spend housing money within the same calendar month that you withdraw the money. As long as you do not hold housing funds over from one calendar month to the next, the funds will not affect your SSI benefits.



ABLE and Medicaid

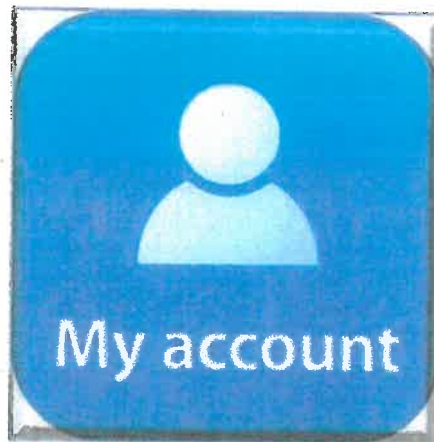
ABLE accounts do not affect your eligibility for Medicaid – called MediCal in California. However, if you take distributions that are not qualified expenses, this could affect your eligibility.



Whose account is it?

While it is clear in the law that the ABLE account belongs to the beneficiary, there are provisions made for those people that cannot manage an account on their own. These provisions allow a parent of a minor or legal guardian of an adult to establish and manage an ABLE account for the benefit of the person.

It is also possible for someone to manage an account through Power of Attorney.



ABLE vs. Trust

ABLE Accounts offer a different kind of savings possibility from a Special Needs Trust. For the beneficiary and/or family, an ABLE Account gives you more flexibility and control over your money than most trusts. Also, the cost of setting up an ABLE account will be lower making it a good option for people with lower incomes. Even if you have a trust account, it is worthwhile to consider opening an ABLE account for the flexibility and control it offers you.



What if the disability subsides?

For disabilities that may come and go such as those due to a chronic illness that flares up then subsides, ABLE accounts are frozen during periods when the person does not have an eligible disability. This means no money can be contributed and no money can be withdrawn.



If the person becomes disabled again and eligibility is reestablished, the account is unfrozen and can be used.

Examples

Example 1: Joe receives SSI and MediCal. Joe needs significant levels of support.

- He currently has no money saved.
- Joe received an inheritance from his grandfather of \$18,000.
- He can roll \$15,000 into an ABLE account (the annual limit) and “spend down” the remaining \$4000 to maintain eligibility for SSI and MediCal.
- Without ABLE Joe can only save \$2000 and would be forced to spend the other \$16,000 immediately to maintain his benefits.
- With his ABLE account he can use the money to get extra support not covered by his state’s disability services. He could use it to purchase equipment such as a computer or hire people to help him do activities he enjoys. He could also choose to save it for future needs.

Example 2: Sarah receives SSI, MediCal and Section 8. She has a part time job where she earns \$17,000 a year.

- She has already saved the maximum amount of money, \$2000, and still maintain eligibility for these benefits
- She opens an ABLE account.
- Her grandparents contribute \$300 each month to her ABLE account, for a total of \$3,600 a year.
- Because she works, her annual contribution cap is higher, up to \$27,140.
- She puts \$15,000 into her account out of her earnings.
- She ends up saving \$18,600 each year in her ABLE account.
- At tax time, using the Saver's Credit, she is can deduct \$2000 from the federal taxes she owes. She puts that savings back into her ABLE account.
- She can use her ABLE account to pay for her day to day expenses as well as to save up for an accessible van or other big ticket item she really needs.

What now?

The Federal law was passed in Dec. 2014. Since then states have been working on passing their own laws in order to enact ABLE accounts within their state.

California's program, CalABLE was launched December 18, 2018. To learn how to establish a CalABLE account, go to www.calable.org.

At least 40 states are operational; most are accepting out of state account holders. You can find the current list and compare programs at the ABLE National Resource Center.

Whether you want to establish an ABLE account out-of-state or in California, it is a good idea to explore the ways in which saving money through an ABLE account could be useful in planning your financial future. Think about how to build this account and set goals for how it might be used to help you establish or maintain your independence throughout your adult life.

Compare programs

If you are considering opening an account, make sure to compare the programs offered by different states. Questions you should get answers to include:

- How does one enroll?
- Is there a minimum deposit to open it?
- Are there any fees for maintaining the account?
- Does the cost differ for in-state and out-of-state residents?
- What are the limits on contributions?
- Are there any limits on withdrawals? Can you withdraw using a debit card?
- Regarding investments, can you choose the level of risk you are willing to live with?
- When can you change your investment options?

Go to the National ABLE Resource Center to compare programs and get your questions answered.⁷

CalABLE has one significant advantage for California residents vs. establishing an account in a different state. If the beneficiary has a CalABLE account, when he or she passes away, California's Medicaid program (MediCal) will not make a claim for reimbursement from the remaining ABLE funds. If the account is in another state, MediCal may file such a claim.

⁷ www.ablenrc.org

Glossary of terms

529 – A college savings plan

529(A) – ABLE account

Account Limit – the maximum contribution limit to an ABLE account

Beneficiary – a person who is eligible for and has opened an ABLE account

Contribution – money that is put into an ABLE account

Annual Contribution – the total amount that can be put into an ABLE account each year

Aggregate Account Limit – the total amount that can be in your account at any time

Distributions/withdrawals – money that is paid out of an ABLE account

Earnings/growth – money that is added to an ABLE account through investments

Functional limitations – Activities that a person cannot do because of their disability

Power of Attorney - the authority to act for another person in legal or financial matters

Public benefits – money set aside by government from taxpayer funds that are used to assist people who need extra support to live. Examples include Social Security, Section 8 housing, food stamps, in-home support services, regional center services etc.

Qualified Disability Expense (QDE) – Any expenditure made from an ABLE account that is permitted under the ABLE act

Rollover – Moving money from one account to another account without incurring a tax liability

Special needs trust – a legal process used to set aside money in a special account for a person with a disability

Spend down – the process of spending money in order to reduce the amount of cash you have

SSI/SSDI – Social security programs established specifically for people with disabilities

Examples of Qualified Disability Expenses

Qualified Disability Expenses do not have to be merely medical expenses. They can include basic living expenditures. While the following list is not exhaustive, some examples of Qualified Disability Expenses are:

Education

- Tuition for preschool through post-secondary education
- Books
- Supplies and educational materials

Housing

- Expenses for a primary residence
- Rent
- Purchase of a primary residence
- Mortgage payments
- Real property taxes
- Utility charges

As long as you spend the housing funds within the same calendar month that you withdraw the money, the housing payments will not affect your SSI benefits.

Transportation

- Use of mass transit
- Purchase or modification of vehicles
- Moving expenses

Employment Support

- Expenses related to obtaining and maintaining employment
- Job-related training

Health, Prevention and Wellness

- Premiums for health insurance
- Mental health, medical, vision, and dental expenses
- Habilitation and rehabilitation services
- Durable medical equipment
- Therapy
- Respite care
- Long term services and supports
- Nutritional management
- Communication services and devices
- Adaptive equipment
- Personal assistance

Assistive Technology and Personal Support

- Expenses for assistive technology and personal support (*e.g.*, a smart phone for a child with autism)

Miscellaneous Expenses

- Financial management and administrative services
- Legal fees
- Oversight and monitoring
- Home improvement, modifications, maintenance and repairs
- Funeral and burial expenses

Resources

CalABLE: www.calable.org

ABLE National Resource Center: www.ablenrc.org

www.realeconomicimpact.org

Federal law: www.federalregister.gov

Information on Special Needs Trusts: www.specialneedsanswers.com/what-is-a-special-needs-trust-13601

Ley de ABLE

**Logrando una mejor
experiencia de vida**

***Cómo ahorrar dinero y
mantener tus beneficios***



**Consejo Estatal de Discapacidades del Desarrollo
Oficina de Los Angeles**

2

Introducción

En 2014, el Congreso de los Estados Unidos aprobó una ley llamada la Ley de ABLE (*Achieving a Better Life Experience*), que representa Logrando una Mejor Experiencia de Vida por sus siglas en inglés. El propósito de esta ley es crear una forma para que las personas con discapacidad puedan ahorrar dinero fácilmente sin perder sus beneficios públicos.

En este folleto usted aprenderá la información básica sobre la Ley de ABLE. Esta es una descripción general solamente; no es una guía completa sobre las cuentas ABLE. En la parte trasera del folleto encontrará recursos en línea que serán más detallados y tendrán información actualizada.

Si hay palabras en este folleto que usted no entiende, por favor vaya al glosario en las páginas 25 y 26 para una simple definición de la palabra o término que se refiere a la Ley de ABLE.

Todas las cantidades de dinero que se discuten en este folleto pueden cambiar en el futuro. Visite la página web del Tesorero del Estado de California para la información más actualizada.¹

La información contenida en este folleto es precisa a partir de diciembre del 2018. Se harán revisiones conforme se tenga nueva información disponible.

¹ www.treasurer.ca.gov/able/

Español: <https://tinyurl.com/ybchzfhy>

Ley de ABLE 2018

Actualmente

Algunas personas que viven con discapacidad y sus familias dependen de una variedad de beneficios públicos proporcionados por los gobiernos estatales y federales para llegar a fin del mes. Los beneficios públicos incluyen Seguridad de Ingreso Suplementario (SSI), Medicaid, estampillas de comida, Sección 8 y otros programas estatales. Estos programas proporcionan un apoyo importante para las personas con discapacidad, pero a menudo no permiten que los individuos ahorren más de un total de \$ 2,000 o que ganen más de \$680 al mes. Esto significa que las personas que tienen estos beneficios no pueden ahorrar dinero y siguen manteniéndose en la pobreza.

En cambio, las personas se ven obligadas a “gastar” cualquier dinero extra que obtienen y esto los lleva a comprar cosas innecesarias que no desean.

Antes de que se aprobara la Ley de ABLE, el único método disponible para ahorrar dinero sin reducir los beneficios era la creación de un fideicomiso para necesidades especiales. Tales fideicomisos son útiles, pero son caros, complicados y no dan al beneficiario ningún control sobre el dinero.



4

Gran mejoramiento

La Ley ABLE da a las personas elegibles una manera sencilla de ahorrar sin el riesgo de perder sus beneficios públicos. También les permite aumentar sus ahorros a través de inversiones sin tener que deducir impuestos de ese crecimiento.

Estas cuentas también se llaman las cuentas 529 (A). Son similares a los planes de ahorro para la universidad llamados planes 529. Las ganancias y las distribuciones no están sujetas a impuestos, siempre y cuando se utilicen para gastos calificados.²

Dentro de ciertos límites, ¡una persona puede ahorrar dinero y aun así recibir sus beneficios completos!

Además de poder ahorrar dinero, el beneficiario es el propietario de la cuenta, lo que le da control sobre su propio dinero



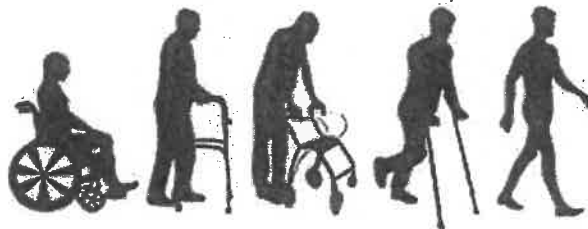
² Vamos a discutir los gastos calificados más adelante en el manual.

Elegibilidad

Para ser elegible, una persona debe estar discapacitada antes de la edad de 26 años. Sí se puede establecer una cuenta si usted es mayor de los 26, siempre y cuando su incapacidad haya comenzado antes de los 26 años de edad.

Puedes ser automáticamente elegible si recibes Ingresos Suplementarios de Seguridad (SSI) o Seguro Social por Incapacidad (SSDI) y cumple con el requisito de la edad.

También, se puede ser elegible si tiene una discapacidad con limitaciones funcionales “marcadas y severas” las cuales duraran por lo menos un año. Esto requerirá la certificación de un médico.



6

El establecimiento de una cuenta

La administración de las cuentas ABLE se establecerá por cada estado. En California, la mesa directiva de CalABLE, bajo los auspicios de la Tesorería del Estado, ha sido designada para administrar el sistema de cuentas ABLE.

Cada persona puede tener sólo una cuenta en un momento dado. La cuenta se puede establecer en cualquier estado. Sin embargo, algunos estados pueden limitar sus cuentas a sólo sus residentes.

Más de 30 estados ya han comenzado a permitir que la gente establezca cuentas ABLE, contando hasta el momento con más de 15,000 cuentas establecidas a nivel nacional. CalABLE entró en funcionamiento en diciembre 2018.

Contribuciones

Cualquier persona, incluso el beneficiario, puede hacer contribuciones a la cuenta ABLE. Estos se hacen después de que se paguen los impuestos. No hay ningún beneficio fiscal para la persona que hace la contribución.³ Los beneficiarios tal vez podrán reclamar un crédito en sus impuestos sobre las contribuciones, tal como se describirán en este folleto posteriormente.



Se podrá contribuir hasta \$15,000⁴ al año hacia una cuenta ABLE. Esto también se conoce como el Límite Anual. Sin embargo un beneficiario que trabaja, tal vez podrá contribuir más, como se describirá en la siguiente página.

La cantidad máxima que puede tener en una cuenta en cualquier momento es decidida por el estado. El límite para las cuentas en California será de \$529,000.⁵

³ Algunos estados tienen beneficios estatales de créditos de impuestos para contribuidores. Los beneficios de impuestos son basados en el estado de residencia del contribuidor, no donde se haya establecido la cuenta.

⁴ Esta cantidad puede ser ajustada en el futuro.

⁵ Esta cantidad puede ser ajustada en el futuro

8

Beneficiarios que Trabajan

Si un beneficiario trabaja él o ella podrá contribuir más a su cuenta que el Límite Anual de \$15,000. Ellos podrán contribuir la cantidad de su ingreso anual bruto, o \$12,140, la cantidad que sea menos. Existen algunas reglas sobre esto:

1. Solo el beneficiario podrá hacer esta contribución extra de su propio ingreso.
2. No podrá haber ninguna cuenta de retiro en base al empleador a nombre del beneficiario, aun cuando solo el empleador sea el que contribuya a esa cuenta.

Contribución regular anual	\$15,000
Contribución por ingresos	+ <u>\$12,140</u>
Cantidad total anual	= \$27,140

Transferencias

Planes de Ahorro para la Universidad 529

Si el beneficiario o un miembro de la familia tienen una cuenta de ahorro para la universidad 529, ese dinero puede transferirse a la cuenta ABLE del beneficiario. Esta cantidad cuenta hacia el límite de contribución anual de \$ 15,000.

Otras cuentas ABLE 529(A)

Usted puede transferir fondos de un 529 (A) a otra 529 (A) de un hermano/a a otro/a hermano/a elegible. Esta reinversión no cuenta para el límite de contribución anual de \$ 15,000

10

Por encima del Límite

Si las contribuciones empujan la cuenta sobre el límite anual de \$15,000, las contribuciones serán devueltas al contribuyente. El último dinero puesto en la cuenta será el primer dinero en regresarse. El beneficiario será notificado cuando esto suceda.



Crédito del Ahorrador

Cuando un beneficiario de ingresos bajos o moderados contribuye a su propia cuenta, es posible que pueda reclamar un crédito fiscal, llamado Crédito del Ahorrador. Para ser elegible para este crédito el beneficiario deberá:

- No ser un estudiante de tiempo completo
- No ser dependiente
- Contribuir a la propia cuenta ABLE
- Deber impuestos
- Como soltero, no ganar más de \$ 32,000 o, como pareja casada, ganar no más de \$ 64,000 de ingreso bruto ajustado por año.

Este crédito fiscal es un porcentaje de la cantidad que el beneficiario contribuyó a su propia cuenta ABLE. Ese porcentaje comienza en 50% para los niveles de ingresos más bajos y se reduce a 10% para aquellos más cercanos al umbral de ingresos altos. El crédito máximo es \$2,000. El monto del crédito reduce la cantidad de impuestos adeudados por el beneficiario. Si el crédito es mayor que la cantidad de impuestos adeudados, no se reembolsará el saldo restante.

Usando su dinero

Usted puede utilizar los fondos para pagar los gastos de discapacidad calificados (**QDE**, por sus siglas en inglés). **QDEs** son gastos que están relacionados con la discapacidad de uno, son para el beneficio del beneficiario, y permitirá que la persona mantenga o mejore su salud, su **independencia** o su **calidad de vida**.

La Ley de ABLE es clara en que los requisitos en lo que es un QDE se debe aplicar de manera libre lo que significa que la mayoría de los tipos de gastos se deben permitir como **QDEs**.

Usted deberá mantener un buen registro de cómo utiliza sus fondos ABLE. Se sugiere que mantenga cada recibo y tenga un registro con una descripción corta de cada compra y como esta es un QDE. Esto le protegerá si el Servicio de Ingresos Interinos (**IRS**) audita su cuenta ABLE.

- El dinero de su cuenta ABLE puede ser utilizado para pagar los gastos de vida básicos
- Los gastos no tienen que ser médicamente necesarios
- Los gastos siguen siendo calificados incluso si hay algún beneficio a los demás; sin embargo, los gastos que son sólo para el beneficio de otro, tales como regalos o donaciones, no son admisibles.
- El dinero utilizado de una cuenta ABLE para los **QDEs** no está sujeto a impuestos

QDEs incluyen ...

- Educación
- Alojamiento / Vivienda
- Transportación
- Apoyo de empleo y entrenamiento
- Tecnología de asistencia
- Apoyos personales
- Salud
- Manejo financiero
- Asistencia legal
- Supervisión / monitoreo
- Gastos básicos de vida
- Funeral / entierro ⁶

Los gastos no calificados estarán sujetos a impuestos y tendrán una multa adicional de 10% del monto retirado. También podrían afectar su elegibilidad para Medi-Cal y otros beneficios públicos.

⁶ Para una lista más extensa, valla a la página final de este folleto

Invirtiendo su Dinero

El dinero en una cuenta ABLE será invertido por los administradores de cuentas contratados por la mesa directiva de ABLE. Además de las contribuciones que realiza, así es como puede crecer su cuenta. Si su cuenta crece debido a las inversiones, ese dinero no será sujeto a impuestos. El otro lado de la inversión es que existe el riesgo de que su cuenta pierda dinero. Por lo general, las inversiones hacen un poco de ambas. Un mes verá aumentar su cuenta mientras otro mes podría disminuir. Con el tiempo, usualmente el dinero que se invierte aumenta más de lo que disminuye.

Cuando usted tiene una cuenta, se le ofrecerán opciones en cómo quiere que su dinero sea invertido. Algunas opciones tendrán la posibilidad de un gran crecimiento; estas opciones también tienen un mayor riesgo de perder dinero. Otras opciones tendrán un bajo riesgo de perder dinero, pero estas también tendrán un menor crecimiento.

Cómo invertir su cuenta ABLE será una decisión importante. No podemos cubrir aquí toda la información que necesita saber acerca de cómo invertir su dinero. Asegúrese de preguntar a la persona que le está ayudando a establecer su cuenta lo que cada opción de inversión es para que pueda decidir lo que será más cómodo para usted.

La administración de cuentas

En California, el administrador de cuentas ha configurado varias opciones de inversión para las cuentas de ABLE. Si usted tiene su cuenta aquí en California, usted podrá seleccionar la que más le convenga para el crecimiento y el riesgo que desea. Usted podrá cambiar su opción de inversión hasta dos veces al año.

Si decide configurar su cuenta en un estado diferente, usted tendrá que aprender las reglas para las cuentas de ABLE de ese estado.

Los administradores de cuentas de ABLE reportarán la información sobre su cuenta al Seguro Social todos los meses.



ABLE y Seguro Social

Probablemente la mejor característica de cuentas ABLE es que los fondos de la cuenta no afectarán sus beneficios públicos. El único beneficio público que pudiera tener un impacto es su beneficio de efectivo del Seguro Social.

En el caso del seguro social, usted puede tener hasta \$ 100,000 en su cuenta y todavía obtener su cheque del seguro social completo cada mes. Una vez que pase esa cantidad de dinero en su cuenta ABLE, sus cheques del Seguro Social se detendrán, pero usted todavía permanecerá elegible. Si su cuenta baja de nuevo a menos de \$100.000, entonces comenzará a recibir sus cheques del Seguro Social nuevamente.

Una nota sobre la vivienda

Los beneficios de SSI pueden ser afectados si se utilizan los fondos de ABLE para los gastos de vivienda y si no se gasta el dinero de inmediato. Para evitar cualquier impacto en sus beneficios de SSI, asegúrese de gastar el dinero de vivienda dentro del mismo mes del calendario que usted retira el dinero. Mientras usted no mantenga fondos de vivienda de un mes al siguiente, los fondos no afectarán sus beneficios de SSI.



ABLE y Medicaid

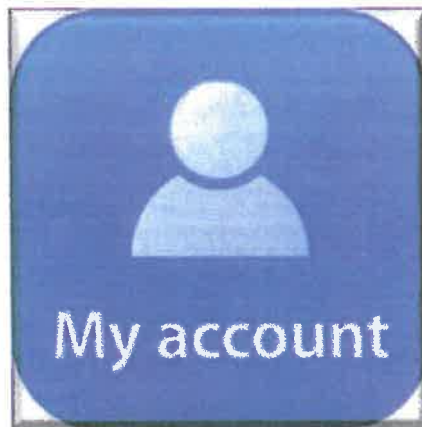
La cuenta de ABLE no afecta su elegibilidad para Medicaid - llamada MediCal en California. Sin embargo, si usted toma distribuciones que no son gastos calificados, esto podría afectar su elegibilidad.



¿De quién es la cuenta?

Mientras que la ley es clara en que la cuenta ABLE pertenece al beneficiario, hay provisiones para aquellos adultos que no pueden manejar una cuenta por sí mismos. Estas disposiciones permiten a un padre de un menor o tutor legal de un adulto poder establecer y administrar una cuenta ABLE en beneficio de la persona.

También es posible que alguien administre una cuenta a través del proceso de Poder Legal (*Power of Attorney*).



ABLE vs. Trust

Las cuentas ABLE ofrecen un tipo diferente de posibilidad de ahorro que un Fideicomiso de Necesidades Especiales. Para el beneficiario y / o la familia, una cuenta ABLE le brinda más flexibilidad y control sobre su dinero que la mayoría de los fideicomisos. Además, el costo de establecer una cuenta ABLE será menor, por lo que es una buena opción para las personas con ingresos más bajos. Incluso si tiene una cuenta de fideicomiso, vale la pena considerar la apertura de una cuenta ABLE por la flexibilidad y el control que le ofrece.



¿Y si la discapacidad se disminuye?

Para las discapacidades que pueden ir y venir, como las que se deben a una enfermedad crónica que aparece y luego desaparece, las cuentas ABLE se congelan durante los períodos en que la persona no tiene una discapacidad elegible.

Si la persona se deshabilita de nuevo y se restablece la elegibilidad, la cuenta se descongela y se puede utilizar.



Ejemplo #1

Jose recibe SSI y MediCal. Jose necesita niveles significativos de apoyo.

- Él no tiene dinero ahorrado
- Jose recibió una herencia de su abuelo de \$ 18,000
- Él puede transferir \$ 15,000 en una cuenta ABLE (el límite anual) y “gastar” los \$ 3,000 restantes para mantener la elegibilidad para SSI y el seguro médico.
- Sin ABLE Jose solo puede ahorrar \$ 2,000 y se vería obligado a gastar los otros \$ 16,000 inmediatamente para mantener sus beneficios
- Con su cuenta de ABLE él puede utilizar el dinero para conseguir apoyo adicional que no ha sido cubierto por los servicios de discapacidad de su estado. Él podría utilizarlo para la compra de equipos, tales como una computadora o contratar personas para ayudarle a hacer las actividades que le gustan. También podría optar por guardarlo para futuras necesidades.

Ejemplo #2

Sara recibe SSI, MediCal y Sección 8

- Ella tiene un trabajo de medio tiempo y ya ha guardado la cantidad máxima de dinero de \$ 2,000, y aun así mantiene la elegibilidad para estos beneficios
- Ella abre una cuenta ABLE.
- Sus abuelos contribuyen \$ 300 cada mes a su cuenta ABLE, por un total de \$ 3,600 al año.
- Porque ella trabaja, su límite de contribución anual es más alto, hasta \$ 27,140.
- Ella deposita \$ 15,000 en su cuenta de sus ganancias.
- Ella termina ahorrando \$ 18,600 cada año en su cuenta ABLE.
- En el momento de los impuestos, utilizando el crédito del ahorrador, ella puede deducir \$ 2,000 de los impuestos federales que debe. Ella vuelve a poner esos ahorros en su cuenta ABLE.
- Puede usar su cuenta ABLE para pagar sus gastos cotidianos y ahorrar para una camioneta accesible u otro artículo importante que realmente necesita.

¿Ahora qué?

La ley federal fue aprobada en diciembre del 2014. Desde entonces, los estados han estado trabajando en aprobar sus propias leyes con el fin de promulgar cuentas ABLE dentro de su estado.

El Programa de California, CalABLE fue lanzado el 18 de diciembre del 2018. Para aprender cómo establecer una cuenta CalABLE, visite www.calable.org.

Por lo menos 40 estados ya están operando y la mayoría están aceptando titulares de cuentas de fuera del estado. Usted puede encontrar la lista actual y comparar los programas en el Centro Nacional de Recursos ABLE.

Si desea establecer una cuenta ABLE fuera del estado o en California, es una buena idea explorar las maneras en que el ahorro de dinero a través de una cuenta ABLE podría ser útil en la planificación de su futuro financiero. Piense acerca de cómo construir esta cuenta y establezca objetivos para la forma en que podría ser utilizada para ayudar a establecer o mantener su independencia a lo largo de su vida adulta.

Compare los programas

Si está considerando la apertura de una cuenta en otro estado, asegúrese de comparar los programas. Preguntas a las que debe obtener respuestas pueden incluir:

- ¿Cómo se inscribe?
- ¿Hay un depósito mínimo para abrirlo?
- ¿Hay algún cargo por mantenimiento de la cuenta?
- ¿En qué se diferencia el costo para residentes del estado y para residentes fuera del estado?
- ¿Cuáles son los límites a las contribuciones?
- ¿Hay límites a los retiros? ¿Se puede retirar usando una tarjeta de débito?
- En cuanto a las inversiones, ¿se puede elegir el nivel de riesgo con el que está dispuesto a vivir?
- ¿Cuándo puede cambiar sus opciones de inversión?

Vaya al Centro de Recursos Nacional de ABLE para comparar los programas y obtener respuesta a sus preguntas.⁷

CalABLE tiene una ventaja significativa para los residentes de California frente a establecer una cuenta en un estado diferente. Si el beneficiario tiene una cuenta de CalABLE, cuando él o ella fallezca, el programa de Medicaid de California (MediCal) no realizará una reclamación por el reembolso de los fondos restantes de la cuenta ABLE. Si la cuenta está en otro Estado, MediCal puede presentar dicha reclamación.

⁷ www.ablenrc.org / Español: <https://tinyurl.com/y89q9v8w>

Glosario de términos

529 - un plan de ahorro para la universidad

529 (A) - cuenta ABLE

Límite de Cuenta – La contribución máxima o el límite para una cuenta ABLE

Beneficiario - una persona que es elegible y ha abierto una cuenta ABLE

Contribución - dinero que se deposita en una cuenta ABLE

Contribución Anual - la cantidad total que se puede poner en una cuenta ABLE cada año

Límite de la cuenta agregada - la cantidad total que puede estar en su cuenta en cualquier tiempo

Distribución/ retiros - dinero que se paga o sale de una cuenta ABLE

Ganancias/ crecimiento - el dinero que se agrega a una cuenta ABLE a través de inversiones

Limitaciones funcionales - Actividades que una persona no puede hacer debido a su discapacidad

Poder Legal (*Power of Attorney*) - la autoridad para actuar en nombre de otra persona en cuestiones legales o financieras

26

Beneficios públicos - dinero destinado por el gobierno de los fondos de los contribuyentes que se utilizan para ayudar a las personas que necesitan apoyo adicional para vivir. Los ejemplos incluyen Seguro Social, Sección 8, cupones de alimentos, servicios de apoyo en el hogar, servicios del centro regional, etc.

Gastos de discapacidad calificados (QDE) - Cualquier gasto realizado desde una cuenta ABLE que está permitido por la Ley de ABLE

Transferencia - Mover dinero de una cuenta a otra cuenta sin incurrir en responsabilidad de impuestos.

Fideicomisos de necesidades especiales - un proceso legal utilizado para guardar dinero en una cuenta especial para una persona con una discapacidad

Gastar - el proceso de gastar dinero con el fin de reducir la cantidad de dinero que tiene

SSI / SSDI – Programas del seguro Social establecidos específicamente para personas con discapacidad

Ejemplos de gastos de discapacidad calificados (QDEs)

Gastos de discapacidad calificados no tienen que ser los gastos médicos solamente. Pueden incluir los gastos básicos de vida. Mientras que la siguiente lista no es exhaustiva, algunos ejemplos de gastos de discapacidad calificados son:

Educación

- La matrícula para el preescolar hasta la educación postsecundaria
- Libros
- Suministros y materiales educativos

Vivienda

- Gastos para una residencia primaria
- Renta
- La compra de una residencia principal
- Pagos de hipoteca
- Impuestos sobre bienes inmuebles
- Cargos de utilidades

Mientras que gasta los fondos de vivienda dentro del mismo mes del calendario que retira el dinero, los pagos de la vivienda no afectarán sus beneficios de SSI.

Transportación

- Uso de los medios de transporte
- Compra o modificación de vehículo
- Gastos de mudanza

Apoyo de Empleo

Ley de ABLE 2018

28

- Los gastos relacionados con la obtención y el
- mantenimiento del empleo
- Entrenamiento relacionado con el trabajo

Salud, prevención y bienestar

- Las primas (los cobros) de seguro de salud
- La salud mental, médicos, gastos de visión y dentales
- Habilitación y rehabilitación
- Equipo médico duradero
- Terapia
- Cuidado/ Respiro
- Servicios y apoyo a largo plazo
- Manejo nutricional
- Servicios de comunicación y dispositivos
- Equipo de adaptación
- Asistencia personal

Tecnología de asistencia y de apoyo personal

- Los gastos para la tecnología de asistencia y apoyo personal (*por ejemplo*, un teléfono inteligente para un niño con autismo)

Gastos varios

- Administración financiera y servicios administrativos
- Honorarios legales
- Supervisión y monitoreo
- Mejoramientos, modificaciones, mantenimiento y reparaciones
- Gastos funerarios y entierro

Recursos

CalABLE: www.calable.org

Español: <https://tinyurl.com/yad6hrxo>

Centro Nacional de Recursos de administración de
ABLE: www.ablenrc.org

Español: <https://tinyurl.com/y89q9v8w>

Instituto Nacional de Discapacidades:

www.realeconomicimpact.org

Español: <https://tinyurl.com/ybar4hou>

Ley Federal: www.federalregister.gov

Español: <https://tinyurl.com/y9nlxshp>

Información sobre fideicomisos para necesidades
especiales: <https://specialneedsanswers.com/>

Español: <https://tinyurl.com/y9nlxshp>



Alzheimer's Disease & Down Syndrome

A Practical Guidebook for Caregivers



Ontg
National Task Group
on Intellectual Disabilities
and Dementia Practices

alzheimer's 
association®

national down syndrome society
ndss.

TABLE OF CONTENTS

Introduction	1
Person-Centered and Relationship-Centered Principles	2
What is Alzheimer's Disease?	3
What is the Connection Between Down Syndrome and Alzheimer's Disease	6
Staying Healthy: Brain and Body	8
The Importance of an Accurate Diagnosis	10
The Importance of a Baseline Assessment	12
Identifying Change Between Baseline and Current Abilities	14
Seeking an Assessment	19
The Importance of a Medication Review	20
Arriving at a Diagnosis	20
Now What?	21
The Natural Progression of Alzheimer's Disease	21
Stages of Alzheimer's Disease	23
Common Physical Complications of Alzheimer's Disease	24
Physical and Cognitive Wellness in Alzheimer's Disease	27
A Note About Sudden Changes	27
Treatment of Alzheimer's Disease	29
General Principles of Caregiving for Adults with Alzheimer's Disease	29
Practical Principles and Tips for Caregivers of Adults with Down syndrome and Alzheimer's Disease	31
Planning for a Meaningful Day	32
Practical Tips in Planning Meaningful Activities	33
Example of a Daily Plan	35
Examples of Activities Appropriate for Adults with Alzheimer's Disease	35
Communication	37
Improving Communication to Improve Connection	37
Learning the Language of Alzheimer's Disease	38
Basic Behavioral Principles	40
A Word About Pain	42
Tying It All Together: Communication and Behavioral Strategies	43
Care for the Caregiver	43
Caregiver Stress	46
Practical Needs Over the Lifespan	47
Planning for the Future	50
Alzheimer's Disease and End of Life	52

FOREWORD

The risk of Alzheimer's disease in adults with Down syndrome can stir deep feelings of fear and anxiety for family, friends, and caregivers who are otherwise trying to focus on supporting and celebrating a healthy and fulfilling adult life for an individual that they love. Education is one way to reclaim some power over a situation where it is impossible to have total control. This booklet was created to help empower families and caregivers with knowledge about the connection between Down syndrome and Alzheimer's disease, suggestions about how to carefully and thoughtfully evaluate changes that may be observed with aging, and guidance about how to adapt and thrive within an ever-changing caregiving role when a diagnosis is made.

For those reading this booklet who are facing an Alzheimer's disease diagnosis for the first time, this booklet aims to be a resource to return to again and again, as different caregiving questions and challenges emerge over time. For those readers who are supporting an individual who has mid- or late-stage disease and already bring with them their own expertise and wisdom from the daily practice of caregiving, perhaps there is information here that sparks new realizations or connections that can be put to use. For those who have lost a loved one with Down syndrome and Alzheimer's disease, perhaps this booklet can help shed light on one unanswered question, provide insight on how to be a support to other caregivers, or help gain further closure on an undoubtedly difficult process.

For readers who are aging well and healthy or are just embarking on adulthood, this booklet aims to empower everyone to take proactive steps to improve and optimize physical, emotional, and cognitive health for a long and vibrant future.

In gratitude to all the caregivers of the world, thank you for taking time to learn about this important topic.

INTRODUCTION

Adults with Down syndrome are now routinely living into their 50s, 60s, and beyond. For many individuals this long and vibrant adulthood is marked by an array of milestones: moving out of the family home, getting a job, becoming an aunt or uncle, finding love, traveling to new places, and trying new and exciting things. The joys that these experiences bring can also be coupled with challenges that adults with Down syndrome may encounter with advancing age. One of the most serious and life-changing concerns that individuals with Down syndrome face as they grow older is the increased risk of developing dementia stemming from Alzheimer's disease.

For anyone receiving the news for the first time, the diagnosis of Alzheimer's disease can be overwhelming. Families and caregivers of adults with Down syndrome can find this diagnosis particularly devastating, as it is often marked by a profound grief for the loss of abilities that had been so hard-earned over the individual's lifetime.

No matter how informed one might be about the increased risk of Alzheimer's disease in Down syndrome, many people feel unprepared when the diagnosis becomes a reality. Family members, loved ones, and caregivers may find themselves in a state of disbelief when they witness changes occurring under their own roof or when the diagnosis is officially made in someone they love. This can be a very emotional time as individuals, caregivers, and families work to fully grasp the implications and impact of this diagnosis.

The intent of this publication is to address the specific concerns related to adults with Down syndrome and Alzheimer's disease and the people who love and support them.

THE GOALS OF THIS BOOKLET ARE AS FOLLOWS:

- 1) To provide proactive and practical guidance about seeking help if early changes are noted, so that an evaluation of possible Alzheimer's disease is made carefully and accurately.
- 2) To empower families and caregivers with practical, directly applicable knowledge to help optimize the well-being of the individual with Alzheimer's disease.
- 3) To provide encouragement, solace, and support for individuals, families, and caregivers for a shared meaningful journey after a diagnosis is made.
- 4) To highlight the importance of honoring the person with Down syndrome throughout their entire life, especially after an Alzheimer's disease diagnosis is made.

PERSON-CENTERED AND RELATIONSHIP-CENTERED PRINCIPLES

Everyone has a story.

An appreciation of an individual's life story is a cornerstone in providing care that is person-centered, and which takes into account his or her culture, life history, lifelong personality, quirks, abilities, strengths, preferences, interests, and values. **Person-centered care** aims to honor the unique physical, medical, mental, social, emotional, and spiritual needs of each individual.

A complement to person-centered care is **relationship-centered care**, which stresses the importance of the various relationships in a person's world that help to support and enhance his or her wellbeing. These nurturing relationships are built on emotional connection and help positively influence care experiences and outcomes for the individual, family, and caregivers.

Person-centered and relationship-centered care embodies humanistic ideals that represent fairly universal goals. While not entirely unique to the needs of individuals with Alzheimer's disease, embracing these principles after a diagnosis can help keep the focus on what is most important when life feels overwhelming.

PERSON-CENTERED PRINCIPLES INCLUDE THE FOLLOWING:

- To be acknowledged as a person with a unique life story.
- To feel loved and safe, while being treated with respect and dignity.
- To be valued and included in his/her community throughout life.
- To be self-directed in choice and decision-making to the greatest extent, whenever possible.
- To be involved in meaningful activity, to feel useful and a sense of belonging.
- To be provided comfort, care and support with patience, compassion and empathy.
- To have care that is focused on what an individual *can* do and not what they can not.

When caring for an individual with Down syndrome and Alzheimer's disease, it is crucial to remember that the person being cared for is still the same unique individual, still continuing on their own evolving and meaningful life story. Through the ebb and flow of the disease, the person's essence remains, whether it's felt directly or kept alive in the memory of those that love and care for him or her.

Life goes on after the diagnosis... It has to! In the coming sections, this booklet aims to provide a roadmap that will hopefully make the journey a little easier for everyone involved.

WHAT IS ALZHEIMER'S DISEASE?

Alzheimer's disease is a cause of **dementia**. The term dementia does not describe a specific disease, but rather a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities. Alzheimer's disease causes problems with memory, thinking, function, and behavior in a way that represents a *decline from the individual's longstanding level of ability*. Symptoms usually develop slowly and get worse over time, eventually becoming severe enough to interfere with daily tasks.

The distinction between the terms Alzheimer's disease and dementia is frequently a source of confusion for families, friends, and caregivers. As mentioned above, the word dementia is a general "umbrella" term that describes a variety of more specific conditions that permanently affect memory and thinking. Alzheimer's disease is the cause of the most common form of dementia that falls under this umbrella, and it is distinguished from other causes of dementia based on its specific characteristics. Practically speaking, the words dementia and Alzheimer's disease are often used interchangeably, both in medical settings and in general conversation. This usage is not wholly incorrect, but it commonly causes confusion for people who are unfamiliar with how the two entities relate to one another. For the remainder of this booklet, the terms Alzheimer's disease and dementia will be used, but do keep in mind that Alzheimer's disease is a *cause* of dementia. Alzheimer's disease affects the brain and causes the observed changes in dementia: such as memory loss, functional decline, behavior and personality changes, and loss of language skills.

TEN EARLY WARNING SIGNS OR SYMPTOMS OF ALZHEIMER'S DISEASE INCLUDE:¹

- **Memory loss that disrupts daily life.** This can include confusion or forgetfulness in a recurrent pattern, enough to interfere with some aspects of the individual's typical daily routine. Early on, forgetfulness typically involves

¹ Adapted from the Alzheimer's Association "10 Warning Signs of Alzheimer's". www.alz.org

difficulty recalling immediate, short-term, or newly-learned information.

- **Challenges in planning or solving problems.** Individuals may show new or worsened difficulty with activities that require multiple steps or tasks of sequencing and planning that they could previously do well. Examples could include repeatedly forgetting to bring a towel or other necessary items into the bathroom at shower time; neglecting to pack more than a granola bar in his or her lunchbox when leaving for the day, or dressing in shorts to leave for work when it's snowing outside.
- **Difficulty completing familiar tasks at home, work, or leisure,** such as decreased work productivity or confusion completing common household or leisure tasks that he or she could previously do well. There may be an overall appearance of poor concentration when attempting to do a chore or a familiar daily activity.
- **Confusion with time or place.** An individual with Down syndrome and early memory problems may appear confused about where he or she is, and may lose track of the day of the week or appear less familiar with a typical daily routine.
- **Trouble understanding visual images and spatial relationships.** Individuals may experience confusion navigating familiar spaces, manipulating common objects, reading, or understanding visual information such as pictures or signs.
- **New problems with words in speaking or writing.** For individuals who have always had expressive verbal language skills (that is, speech), language may become more bland or simple, or vocabulary and word choice may become more limited. Difficulties in receptive language (the ability to hear and understand verbal language) may lead to a difficulty answering questions or following directions.
- **Misplacing things and losing the ability to retrace steps.** Individuals may appear more absent-minded and apt to misplace or lose items. Examples may include no longer putting a lunchbox away in its usual place in the kitchen at the end of each day or putting things in unusual places (an open mayonnaise jar left in a cupboard, dirty clothes mixed into the drawer with clean items, etc.). When individuals become more forgetful of where something was put down, there may be increased accusations that other people are stealing items that are in fact misplaced.

- **Decreased or poor judgment.** Some individuals with early memory changes may forget to lock their front door, discard items of value, or show new impulsivity or poor/worsened safety awareness.
- **Withdrawal from social activities.** Individuals may start avoiding social opportunities due to the anxiety, stress, or confusion about the changes he/she is experiencing. Activities that may have once reliably provided joy and excitement may suddenly seem overwhelming for individuals experiencing memory problems.
- **Changes in mood and personality.** Individuals may show an array of new or worsening negative emotions along with confusion including suspicion, paranoia, anxiety, sadness, tearfulness, and depression.

KEY DISTINCTIONS REGARDING EARLY WARNING SIGNS

Everybody is entitled to have a bad day now and then. Misplacing a pair of eyeglasses once in a while or forgetting the name of a distant relative at a family reunion does not necessarily indicate that dementia symptoms are starting to emerge. When considering the warning signs listed above, note that these symptoms should constitute a regular pattern and interfere with daily activities in a way that represents *a change from the individual's previous level of ability*. This is a key distinction that will be reinforced throughout this booklet.

There are numerous other possible conditions that can cause symptoms of confusion or forgetfulness. A diagnosis of Alzheimer's disease needs to be approached carefully, and considered as a possibility only if there are no other identified medical or psychiatric causes identified that may have otherwise brought on symptoms or changes that are observed. The list of alternate explanations for early changes that may be observed is broad at first, and can include a wide range of possible causes. Examples include: an acute infection, a sudden medical illness, a stroke, new or recurrent seizure activity, an adverse reaction to a medication, worsening depressed mood, acute grief reaction, trauma or triggering of past trauma, worsened anxiety, or other ongoing personal stressors that are causing a significant emotional burden on the individual. Thus, it is important to think broadly at first, so as not to miss recognizing other common conditions contributing to changes that are observed.



WHAT IS THE CONNECTION BETWEEN DOWN SYNDROME AND ALZHEIMER'S DISEASE?

Alzheimer's disease is caused by changes to brain cells, causing irreversible damage that leads to a gradual slowing down and failing of brain function. The damage is brought on by the accumulation of protein substances in the brain that disrupt brain cell health and signaling between cells. The build-up of these proteins contributes to abnormalities that are commonly referred to as "plaques" and "tangles," based on the way in which they appear under a microscope.

Alzheimer's disease and Down syndrome share a unique genetic connection. In the typical population, people have two copies of each chromosome, to equal a total of 46. Recall that in Down syndrome, individuals have a full or partial third copy of chromosome 21 (hence, the name **trisomy 21**). Chromosome 21 carries a gene for the protein that is produced in excess in Alzheimer's disease, leading to the buildup of **beta-amyloid**, the protein responsible for forming the plaques that cause permanent damage to brain cells. Since individuals with

Down syndrome carry three copies of this chromosome in their cells, they have an additional overproduction of this brain-toxic protein. Scientists are still working to fully understand the role of all of the other genes located on chromosome 21, as several of them are felt to contribute to the accelerated aging process that's seen in Down syndrome. These unique properties of chromosome 21 are associated with elevated risk of premature Alzheimer's disease for adults with Down syndrome specifically. The same risk is not seen as distinctly in adults with other forms of intellectual disability.

While it is well-established that there is an elevated risk for Alzheimer's disease in adults with Down syndrome as they grow older, it is important to emphasize that this diagnosis is **NOT** inevitable. For reasons that are still not fully understood, some individuals with Down syndrome will develop Alzheimer's disease as they grow older, while some individuals will live their life without showing the outward changes of dementia. Current estimates suggest that Alzheimer's disease affects more than 30% of people with Down syndrome in their fifties and 50% or more of people in their sixties, with risk increasing incrementally with advancing age thereafter.

Although risk increases significantly with each decade of life after 50 for adults with Down syndrome, it is vitally important to make sure that a diagnosis of dementia is approached carefully, and not given prematurely or without a thorough investigation. At the first signs of someone acting even slightly differently than usual, it is important to keep in mind that there are many other possible contributors to changes that are seen with age. There are several common medical conditions that adults with Down syndrome experience as they move through adulthood and into older age, many of which can cause vague symptoms of confusion if not properly identified and addressed.

These common conditions were reviewed in more detail in the publication, **Aging and Down Syndrome: A Health and Wellbeing Guidebook**, available through the National Down Syndrome Society. Readers are strongly encouraged to obtain this booklet for additional information on this topic, as well as other health-related resources for adults with Down syndrome who are growing older.

It is important that health care providers, family, and other caregivers remain vigilant for signs of these conditions, as many of them can have features or symptoms that can mimic some aspects of Alzheimer's disease.

Available through the
National Down Syndrome
Society at ndss.org.

COMMON MEDICAL CONDITIONS IN AGING ADULTS WITH DOWN SYNDROME:

- **Vision loss/impairment** due to early cataracts (a clouding of the lens of the eye) and keratoconus (a distortion of the shape of the eye, which can impair vision)
- **Hearing loss**, which occurs more commonly with age and is often made worse by wax impactions, especially in small and narrow ear canals.
- **Hypothyroidism**, a condition that causes an underactive thyroid gland, which contributes to symptoms of fatigue and mental sluggishness.
- **Obstructive sleep apnea**, a sleep disorder that leads to poor quality, non-restorative sleep that makes people feel sleep-deprived even if they appeared to have had a full night's sleep.
- **Osteoarthritis**, which can cause pain and stiffness that can make tasks more difficult to perform or can contribute to overall irritability.
- **Atlantoaxial instability and cervical spine disease**, caused by congenital and/or degenerative changes in the region of the spine



located at the base of the skull and neck, which can have a variety of effects on normal movement, strength, and function.

- **Osteoporosis**, a condition that causes thinning and weakened bones that can lead to fractures which cause pain and impaired mobility.
- **Celiac disease**, an autoimmune disease that causes an inability to digest wheat and gluten, which can lead to stomach distress, vitamin deficiencies, weight loss, and overall irritability.

STAYING HEALTHY: BRAIN AND BODY ¹

It is never too late or too early to incorporate healthy habits! Maintaining good physical health and brain health throughout life is an important goal for everyone to strive to achieve. There is also growing evidence that these habits and interventions can help lower the risk for the development of dementia. There are many practices that adults with Down syndrome can incorporate into their lifestyle that will help promote cognitive and physical health over their lifetime. These lifestyle habits are important for all individuals with Down syndrome whether they are young and thriving if they've reached old age, or if they've developed Alzheimer's disease.

¹ Adapted from the
Alzheimer's Association "10
Ways to Love your Brain."
www.alz.org

Incorporating the following into daily life can help to optimize overall health and well-being and minimize additional risk factors that can affect brain function over time.

- Engage in **regular cardiovascular exercise** that raises the heart rate. Healthy blood flow to the heart helps promote healthy blood flow to the brain.
- **Stay mentally stimulated and engaged.** Adults with Down syndrome are encouraged to continue to build and expand lifelong learning, by trying new things and setting new goals that help keep their brain engaged and working hard. Aim to regularly add in challenges with a new game or jigsaw puzzle to activate the brain. For adults with Alzheimer's disease, it is important to stay engaged in familiar tasks that are both mentally stimulating and pleasurable, to help reinforce existing strengths and abilities.
- **Don't smoke.** Make every effort to quit smoking. Limit exposure to second-hand smoke as well.
- **Lower risk factors for stroke and heart disease,** including obesity, high blood pressure, high cholesterol, and diabetes. Make good heart health a priority and get regular checkups and screenings.



- **Avoid preventable head trauma.** Brain injury can raise the risk of dementia. Wear a seat belt, use a helmet when riding a bike, and take any other necessary steps to avoid any preventable trauma to the brain.
- **Eat a healthy and balanced diet.** Adults with Down syndrome are at high risk of being overweight in adulthood, but with a healthy diet and exercise, this risk can be reduced. Aim to eat a diet that is low in fat and high in vegetables and fruit to help maintain a healthy weight. Limit salt and sugar intake.
- **Get rest.** Poor sleep can affect memory, concentration, and thinking. Adults with Down syndrome are also at risk of sleep apnea. Pay attention closely to sleep habits, aim to get a restful and restorative overnight sleep, and bring any additional sleep concerns to the attention of a health care provider.
- **Take care of mental health.** Untreated depression and other mood disorders can cause impairment in thinking and memory. Seek out help for concerns related to depression or anxiety and help create strategies to help minimize and manage stress.
- **Stay socially engaged.** Keeping up a social network of family, friends, and peers and engaging in activities that are fun and meaningful is instrumental to emotional health and wellbeing throughout lifetime. Look for ways to be part of the local community through volunteering or joining a club. Keep up with hobbies and interests that bring joy.

THE IMPORTANCE OF AN ACCURATE DIAGNOSIS

The diagnosis of any form of dementia is based primarily on clinical information, i.e., the history, signs, and symptoms that are brought to the attention of a health care provider. Currently, there is not one laboratory test, neuropsychological examination, x-ray, or brain scan that makes the diagnosis of Alzheimer's disease. Instead, the determination falls primarily to the health care provider who is assessing the individual and making a judgment about whether there is ample evidence to support a dementia diagnosis. Alzheimer's disease remains a complex diagnosis to make in the general population, in part due to natural variability in how medical providers review and interpret the information that they are given. However, in the hands of an experienced health care provider, a carefully made diagnosis is absolutely possible.

Making a dementia diagnosis in adults with Down syndrome can seem daunting for many health care providers due to a variety of factors: the inherent variability of baseline intellectual ability, the lack of standardized diagnostic tests, and the lack of any specialty training among health care providers. Most health care professional training still lacks any dedicated education or clinical experience in working with adults with intellectual and

developmental disabilities, including adults with Down syndrome. Despite these challenges, it is entirely possible to achieve a careful and thorough assessment of an adult with Down syndrome and suspected memory changes. Currently, the best assessment starts with a well-informed review of the individual's history, accounting for longstanding baseline abilities and a description of how and when these abilities started to change.

The diagnosis of Alzheimer's disease is one that should not be given casually or hastily. It is important that the diagnosis is made with a confidence that all other possible conditions or issues have been thoroughly investigated and addressed. Many health care providers are aware of the connection between Alzheimer's disease and Down syndrome, but this knowledge also at times leads to diagnoses that are made prematurely, without exploring the multitude of other common health conditions that could be playing a primary or key contributing role.

Through increased awareness of and vigilance for common medical, psychiatric, and emotional contributing factors, caregivers can help call attention to the possibility of these coexisting conditions. As mentioned earlier, there are several common conditions that adults with Down syndrome may encounter, most of which can cause symptoms that can mimic memory loss. If these conditions are present but not properly investigated, identified, or treated, there is a missed opportunity to address conditions that could potentially modify or improve symptoms. The same is true of mood disorders, such as undetected or untreated depression or anxiety, which can contribute to symptoms of confusion, poor concentration, inattention, or loss of interest to participate in tasks or activities.

An accurate assessment should pay close attention to changes that may be occurring in one's mood or behavior. In some cases, an untreated primary mood disorder may account for all of the symptoms that may have otherwise been characterized as signs of memory loss. Even more commonly, mood changes may co-occur with the onset or progression of dementia and may worsen or intensify certain symptoms. Thus, identification of mood disorders allow an important treatment opportunity that may carry great positive impact.

In summary, it is imperative that a medical provider evaluates for other conditions that may be either causing directly or contributing to the changes observed, while also working to confirm that the key changes identified are indeed suggestive of Alzheimer's disease. The following sections will provide a basic framework about seeking out a thoughtful and thorough assessment to help caregivers advocate for an accurate and careful diagnosis.



THE IMPORTANCE OF A BASELINE ASSESSMENT

An individual's history is the cornerstone of any dementia diagnosis. Recall that the diagnosis is not based on a single test result or brain scan, but instead on the medical provider's assessment of all of the symptoms taken into context for each individual. A core feature of an Alzheimer's disease diagnosis is the progressive loss of memory and other daily skills that *represent a decline from the individual's longstanding level of ability*. Therefore, any judgments made by a medical provider must be based on some basic understanding of what comprised the individual's baseline ability throughout their lifetime.

In adults with Down syndrome, or any form of intellectual disability, so-called 'baseline' abilities are highly variable. Some individuals achieve high-level academic skills, are voracious readers or accomplished artists, live independently, and take public transportation to their jobs. Some individuals may have never learned to tie their own shoelaces or to use the bathroom without help. Each individual is different and unique. This wide variability in possible lifelong abilities means that no assumptions can be safely made at the time of first assessment without gathering information for a baseline description. *Recognition of a progressive change from these baseline abilities is the cornerstone of an Alzheimer's disease diagnosis.*

Baseline abilities can and should be documented and tracked in two forms, **objective** and **subjective** information.

1. **Objective memory performance** refers to a concrete, measurable demonstration of skills. This is achieved by documenting a range of skills, abilities, and strengths that the individual has achieved in life. Some form of objective memory testing is recommended to be undertaken by age 35 or 40 so that there is a formal record of memory performance that could be used for comparison in the future if changes are noticed.

Specialized assessments involving some form of formal memory testing can be performed by a memory specialist – a geriatrician, neuropsychologist, neurologist, or psychiatrist. Ideally, an evaluation should be performed by a specialist with experience and expertise in assessing individuals with intellectual disabilities, and availability of such specialists is worth inquiring about in your area. Assessments should be adapted appropriately for the individual's baseline intellectual disability, as many standardized tests developed for the general population are inappropriate for individuals with intellectual disability. Unlike assessments that are done in the typical population, memory evaluations that are based on comparison to peers of a similar age have no practical use.

There are many simple ways of informally collecting objective examples of one's baseline abilities as well. Writing samples, drawings, art projects, and math worksheets, and personal journals are valuable pieces of information that can be compiled and used for reference of baseline skills and used for comparison if abilities start to falter with age. A collection of this information could also be done in other forms, like a video recording of the individual performing typical activities or talents: swimming, singing, using the computer, counting coins, or helping make cookies. Compiling a 'scrapbook' of abilities and achievements over one's adult life can be a very positive and fun activity that would also serve as very valuable reference later in life when tasked with reflecting back upon changes over time.

2. **Subjective memory performance** refers to a narrative description of the unique baseline abilities and characteristics of an individual. Family members or longstanding caregivers who have known the individual for several years or more are usually best equipped to describe baseline abilities and characteristics. For younger people, a baseline description of abilities is something that could be compiled like a journal or a story throughout adulthood, documenting achievements while the individual is thriving and doing well.

Baseline descriptions can also be reconstructed historically or retrospectively, detailing lifelong abilities, strengths, and weaknesses throughout the individual's lifetime through the recollections of people who know the individual well. Subjective information is often what is heavily relied upon in memory assessments, especially if there are no

other objective measures or formal baseline memory testing that exists representing baseline abilities. A clear outline of baseline function provides a direct comparison that can specify observed changes and may prompt further discussion with a health care provider or specialist. Changes are noteworthy if they represent a significant difference based on their own individual lifelong abilities. This will be detailed further in the next section.

IDENTIFYING CHANGE BETWEEN BASELINE AND CURRENT ABILITIES

There are various strategies that one may use to document and track baseline abilities over time, but a structured and comprehensive approach is recommended to capture abilities in a range of skills. **The NTG-Early Detection Screen for Dementia (NTG-EDSD)** is an early detection and screening instrument designed specifically for use by caregivers and staff to identify early signs and symptoms of dementia in adults with intellectual disability. It is important to note that the NTG-EDSD is not used to diagnose dementia, but it can screen for specific areas of change that can further direct discussion and evaluation with a health care provider. The NTG-EDSD can be used to document baseline abilities and then tracked on a periodic basis to survey for any observed changes from baseline in areas such as memory, behavior, daily care abilities, and general functioning. This may be done yearly in preparation for an annual medical examination or done more frequently if other concerns arise. If changes are noted, this screening tool can help prompt caregivers to seek a formal assessment from a health care provider. Links to the NTG-EDSD and related materials can be found on the NDSS website as well as at www.aadmd.org/ntg.

Another strategy is to use a **narrative format**, which allows the caregiver or family member to be descriptive in detailing typical patterns or abilities. The worksheet that follows outlines an example framework in which such a narrative could be constructed, highlighting seven different categories of baseline ability that are important to track over time. The "**baseline**" portion is best completed by someone who has known the individual for several years or more and can confidently describe or recall typical abilities and milestones achieved over adulthood. The "**current**" portion is best completed by someone familiar with typical day-to-day abilities that are observed presently.

For individuals who are doing well and showing no signs of change or concern, this narrative worksheet is also highly useful for documenting baseline abilities in a proactive fashion. This helps provide an ongoing narrative record of what an individual has achieved throughout adulthood.

BASELINE ABILITIES AND CHARACTERISTICS

Describe the individual's abilities that are/were typical of what he/she can/could do throughout adulthood. Be as descriptive as possible!

FUNCTION	How independent was the individual in performing self-care tasks throughout lifetime – i.e.; bathing, dressing, toileting, grooming, eating, and walking?
SKILLS	What academic skills were achieved? What chores or responsibilities could the individual perform around the house? What jobs has he/she held? What activities would he/she typically do at day program? Any other talents or abilities throughout lifetime? Hobbies, sports, other favorite activities?
MEMORY	Could the individual learn and recall names of familiar people? Keep track of the day of the week and daily or weekly schedule? Know his/her way around familiar areas? Reliably remember short term or newly-learned information? Could he/she reliably recall recent past events? Any particular memory talents or skills?
BEHAVIOR	What behaviors have been present throughout adulthood? Self-injurious behaviors? Aggression towards others, either verbal or physical? Self-talk or imaginary friends? Any other quirks or rituals? Has the individual required a behavior plan? If so, what strategies have been helpful? Any other typical pattern or triggers to behaviors over lifetime?
LANGUAGE	Could the individual express him/herself verbally to let his/her basic needs be known? Speak in full sentences? Hold a conversation? If he/she was never verbal, how were needs expressed? Could the individual understand verbal language and answer questions appropriately or follow a verbal instruction?
PERSONALITY	Did the individual seek out peer relationships? Was he/she social? Well-liked by others? Did he or she show preference for routine and structure? How else would you describe his or her personality?
MOOD	What was the individual's mood like most days? Were there mood swings? Any mood/psychiatric issues that recurred or persisted throughout adulthood? Did he/she receive psychiatrist or therapist? Any past psychiatric hospitalizations?

CURRENT ABILITIES AND CHARACTERISTICS

Now describe the individual's current abilities - highlighting, when applicable, the areas in which changes are noted compared to what was described above in the baseline section.

FUNCTION	Lately, how independent is the individual in performing self-care tasks? Bathing, dressing, toileting, grooming, eating, and walking? Have changes been observed in functional abilities compared to baseline? Describe.
SKILLS	Compared to what was outlined at baseline, how have typical daily skills and abilities changed? Is the individual still participating in baseline abilities, routine tasks, and household chores? Has job performance or participation in day program activities changed?
MEMORY	What concerns are there about memory skills? Increased forgetfulness, confusion, disorientation, poor concentration? Repeated stories or repeated questions? Forgetting names, mixing up days of the week, etc? What has changed compared to baseline?
BEHAVIOR	How have behaviors been lately? Are new behaviors emerging? Has there been a change in the frequency or intensity of typical behavior patterns? Any other new triggers for behaviors noted? What tends to make behaviors better?
LANGUAGE	Have language abilities changed lately? Is the individual able to let his or her needs known per usual? Has vocabulary gotten smaller or verbal output declined overall? Difficulty finding words? Difficulty hearing and answering questions, or difficulty following verbal instructions?
PERSONALITY	Any recent shifts in personality? Increased irritability, stubbornness, intolerance to change, withdrawal? Any other observed changes compared to baseline?
MOOD	Have there been observed changes in typical mood? Increased mood swings, tearfulness, sadness, withdrawal? Hearing voices? Seeing or hearing things that are not there?

After reading through each section individually you are encouraged to *compare and contrast baseline vs. current abilities and note if any patterns are present*. Observe if any domains, i.e., mood, behavior, personality, are starting to shift noticeably while others staying stable over time? Is there a time frame when changes started to emerge? Are there any other observations or thoughts that arise when reviewing the information altogether?

Both the NTC-EDSD and this narrative exercise can be used as a stepping stone to help identify patterns of change and to prompt further thought about what else may be contributing to changes that are observed. Caregivers should look at the timeline over which changes have been noted and reflect upon whether any other important event or change may have happened at the same time. Was there a significant life event, a loss, a personal stressor, a change or upheaval in the home setting or day program? Was a new medication started? A medication stopped? Were there any injuries, acute illnesses, surgeries, or hospitalizations?



OTHER SYMPTOMS TO CONSIDER WHEN MEMORY CONCERNS ARISE:

In addition to the narrative information included in the worksheets, **reflect further on key symptoms**, looking either for entirely new concerns or a worsening of longstanding symptoms. This can help identify other contributing factors that may need further evaluation

- Any new **change or decline in vision**
- Any new **change or decline in hearing**
- Any **dental concerns**, especially those that could be contributing to pain or change in eating habits
- **Seizure activity**, either new suspected seizure activity or an increase in seizure frequency in an individual with a known seizure disorder
- New or worsened **incontinence of bowel or bladder**
- **Weight fluctuations**, either a noticeable gain or loss
- **Change in appetite**
- Any observed **swallowing difficulties**
- **Sleep difficulties** or other abnormal sleep patterns or habits
- New **difficulty walking** or changes in walking abilities
- **Falls** or increased risk of falls
- **Pain**, either directly reported or suspected through observation of facial expression or other non-verbal clues

Applying the same approach used in the narrative worksheets, it is important to highlight the areas where *change* is noticed compared to the individual's typical lifelong symptoms. Sharing this information with a health care provider can help prompt additional investigation for other underlying causes of change.

SEEKING AN ASSESSMENT

When memory concerns first arise, many individuals seek attention first from a health care provider. There are several common medical conditions that may occur in adults with Down syndrome as they grow older. Many of these conditions can cause symptoms that can be misinterpreted as confusion or poor concentration, so it is important to keep these in mind when seeking out an evaluation for the first time.

EXAMPLES OF NEXT STEPS COULD INCLUDE:

- **Vision and/or hearing testing** to assess for sensory losses
- **Blood work** to evaluate for any disturbances in electrolytes, vitamin deficiencies, or thyroid dysfunction, or to screen for celiac disease
- A **sleep study** to assess for sleep apnea
- **X-rays or other imaging** to assess for arthritis or degenerative changes in the large joints or cervical spine (neck)
- **Assessing for depressed mood** or other underlying mood disorder



THE IMPORTANCE OF A MEDICATION REVIEW

A thorough review of the medication list is an important initial step in the evaluation of any new onset change or decline from baseline. Aging individuals may see multiple doctors and specialists, many of whom may prescribe medications or change treatment plans without collaborating with one another. Anytime the medication list expands or new prescriptions are started, there is an increased risk that prescribed medications may interact negatively with one another or may combine to make side effects more potent.

There are numerous types of medications that can have adverse effects on alertness and mental clarity, which can contribute to symptoms of confusion, dizziness, and walking and balance disturbances. All medications, including prescribed, over-the-counter, and herbal medications should be periodically reviewed with a health care provider to make sure that all medications are necessary and that their benefits outweigh any unwanted risks. This is especially true at times of transition, such as when an individual is being discharged from the hospital, seeing a new doctor, or moving to a new residence. When a concern is raised about new or worsening confusion, a careful evaluation of the medication list is always an important and necessary step. A thorough review may reveal a new medication that the individual may not be tolerating, or may call attention to a recent dose adjustment or discontinuation of a longstanding medication.

ARRIVING AT A DIAGNOSIS

Alzheimer's disease is a diagnosis of both *inclusion* and *exclusion*. In other words, evidence supporting a diagnosis should *include* a convincing history (progressive loss of *memory and skills* compared to one's *baseline functioning*) and should *exclude* all other plausible conditions that could have caused the changes observed (i.e., grief, acute infection, depressed mood, medication side effects, untreated severe sleep apnea, dehydration and so on).

If any coexisting medical or psychiatric conditions are identified, efforts should focus on treating them to the fullest extent possible. For example, if an individual is found to also have depression, sleep apnea, or an underactive thyroid, a treatment plan to address these underlying issues should be devised with a health care provider. Identifying and treating any and all potentially correctable or modifiable conditions is vitally important, followed by observation of any effect the treatment had on the individual's thinking and function. If the decline is still noted despite best efforts to improve or treat all other contributing conditions, then this further strengthens evidence of an Alzheimer's disease diagnosis.

NOW WHAT?

As earlier sections have emphasized, it is critically important to ensure that an Alzheimer's disease diagnosis is made thoughtfully, methodically, and carefully. However, oftentimes medical encounters are so focused on making the diagnosis, that there may be little time left for discussion about the various implications of the diagnosis. This "now what?" discussion that should follow an Alzheimer's disease diagnosis should ideally be both person-centered and relationship-centered, addressing the practical, day-to-day concerns that can affect the wellbeing of the individual and his or her caregivers. This topic is of paramount importance, and this section aims to provide more clarity to the questions that commonly arise after the diagnosis is made.

THE NATURAL PROGRESSION OF ALZHEIMER'S DISEASE

Alzheimer's disease is very broadly characterized by a gradual decline that progresses through three stages: **early, middle, and late stage**. These stages are distinguished by their general features, which tend to progress gradually throughout the course of the disease, accompanied by incremental loss of abilities and skills and increased need for support, supervision, and assistance.

Each individual is different and will experience changes in his or her own unique way. The stages of Alzheimer's disease do not appear as one pure complete cluster of symptoms or features, but rather a range of losses and changes, as some features may appear earlier or later than others and may be intermittent. The table that follows provides a general description of the type of changes that are typically seen at each stage. It is helpful for caregivers to have a general sense of where an individual may stand along the overall progression of Alzheimer's disease, whether it is early, middle, or late stage. This awareness helps prompt vigilance for other changes that may be encountered later in the disease course and can help with broader concepts of decision-making and priority-setting in an individual's overall care.

SHARING THE DIAGNOSIS

It is important that the diagnosis of Alzheimer's disease be shared with the individual with Down syndrome in words and concepts that can be readily understood. A lengthy discussion about the nature of the disease may not be appropriate for most individuals, but it is important to look for an opportunity for a direct and honest discussion about the diagnosis and the effect it may have on him or her. For some individuals with Down syndrome, explaining that feelings of forgetfulness and confusion are due to a disease may even bring a sense of relief. Validation of feelings of frustration, anger, or sadness is important as the individual copes with these changes, emphasizing that the forgetfulness is not his or her fault.



Similarly, sharing the diagnosis, even in very general terms with housemates, friends, and peers can be very helpful, as they may often be confused or scared by changes that they are witnessing. Friends can be a great support and often want to be helpful, particularly if they're given the basic understanding that the individual has a problem with his or her memory. If not addressed, often housemates or peers will have difficulty understanding why their friend's behavior is changing or why they're getting 'extra' attention or not following rules like they should. Allowing friends to be involved in the process can be a great way of letting them follow their own natural instincts to help while allowing the individual to maintain lasting connections with his or her friends and housemates.

STAGES OF ALZHEIMER'S DISEASE

Adapted from "Stages of Alzheimer's", Alzheimer's Association, www.alz.org

EARLY STAGE	MIDDLE STAGE	LATE STAGE
Episodes of short term memory loss	More pervasive short term memory loss with some decay of long term memories	Profound memory impairment, including long-term memories
Difficulty recalling recent events	Daily forgetfulness and confusion	Difficulty recognizing family
Telling the same story repeatedly	Deterioration or loss of some or all household chores or other daily tasks	Full dependency on others for all personal care tasks
Asking the same question repeatedly	Increased level of assistance needed for some aspects of personal care (e.g., bathing, tooth brushing, shaving)	Loss of mobility – primarily wheelchair or bed bound
Difficulty learning new information (like names)	Dependent on the prompts and reminders of caregivers to get through an average day	Significant loss of expressive speech (i.e., 6 words or fewer in vocabulary, mainly just vocalizations)
Difficulty finding the right word	Disorientation to concepts of day of week, recurring events, routine, schedule	Total incontinence of bowel and bladder
Vocabulary becomes smaller or simpler	Increased difficulty recognizing people and recalling names	
Difficulty following verbal instructions	Poor judgment and safety awareness	
Appearing more "lost", confused, or distracted	Difficulty navigating familiar places, getting lost	
Difficulty performing routine tasks, or forgetting steps of complex tasks	Mood and behavior fluctuations – agitation, poor frustration tolerance, difficulty coping with times of transition or change	
Decreased/impaired work performance or participation in day program activities	Wandering, restlessness	
Needing more reminders to get through a routine day	Physical changes related to progressive dementia: -New onset seizures -Urinary incontinence, possibly fecal incontinence -Swallowing dysfunction -Worsened gait and mobility, more unsteady, weak, or timid	
Mood or personality changes – more irritable or easily frustrated, paranoid or anxious		
Misplacing things or difficulty finding things in their usual location		

COMMON PHYSICAL COMPLICATIONS OF ALZHEIMER'S DISEASE

As Alzheimer's disease progresses, physical functioning can become progressively impaired and can mirror the changes occurring with brain function and memory. While every individual with Alzheimer's disease will not encounter all of these issues, the conditions occur frequently enough that caregivers are encouraged to be aware of them so they feel better prepared to seek help early if changes arise.

SWALLOWING DYSFUNCTION AND EATING DIFFICULTIES

As Alzheimer's disease progresses, it is common to develop progressive difficulty eating or safely swallowing certain foods or fluids. This is due in part to memory loss, as individuals may not: i) readily remember that they have or haven't eaten, ii) remember how to properly chew/swallow or handle certain foods or utensils, or iii) recognize certain hunger or thirst cues. As the disease progresses, coordination and strength of swallowing muscles deteriorate, and the cough reflex that protects food/fluid from going into the lungs may weaken. As swallowing and eating become slower and more challenging, mealtime may take much longer than usual and there may be a further risk of decreased nutritional intake and weight loss. Swallowing difficulties also increase the risk of taking food or fluid accidentally into the lungs, which can lead to choking and possibly an infection. This process is called **aspiration**, with the resulting lung infection typically referred to as **aspiration pneumonia**.

CAREGIVER STRATEGIES TO HELP WITH SWALLOWING AND EATING DIFFICULTIES:

- Allow more time for eating
- Provide finger foods that are easy to pick up
- Provide smaller portions of food more frequently during the day
- Observe for any changes in swallowing abilities, such as coughing or gagging while eating
- Discuss swallowing or eating concerns with a health care provider to determine whether a more formal evaluation of swallowing is necessary.
- Cut food into smaller-sized bites

INCONTINENCE

Bladder and bowel control deteriorates as brain function worsens, so the development of incontinence very commonly occurs as Alzheimer's disease progresses. Memory impairment leads to: 1) difficulty interpreting bodily

cues that indicate the urge to use the bathroom, 2) inability to find the bathroom or properly ask for help, or 3) difficulty sequencing the typical toileting routine when in the bathroom. Individuals are often physically slower and less steady on their feet, and thus less able to dash off to the bathroom quickly, which can lead to accidents.

CAREGIVER STRATEGIES TO HELP WITH INCONTINENCE:

- Provide verbal reminders to use the bathroom.
- Mark the bathroom door with something familiar to the person.
- When an individual loses independence with toileting skills, help bring him or her to the bathroom every 2-3 hours while awake to help avoid accidents.
- Check for soiled sheets or wet bed clothes overnight.
- Aim to limit fluids before bedtime.

SEIZURES

Individuals with Alzheimer's disease and Down syndrome are at increased risk of developing seizures as dementia progresses. It is important to be aware of this possible eventuality, to be watchful for any symptoms and act quickly to get medical attention. Caregivers should watch for any new, sudden onset of a change in alertness, uncontrollable rhythmic jerking of the arms or legs, unexplained staring spells, startled movements or episodes of loss of consciousness.

First-time seizures are not always witnessed, so it's important to keep the possibility of seizures in mind if an individual with Alzheimer's disease is found on the ground or floor for unknown reasons or if there is a new pattern of unexplained falls. If new seizure activity is witnessed or suspected, then further attention from a health care provider is recommended. Caregivers can greatly enhance the medical assessment for seizures by providing as richly detailed a description of the event as possible.



CAREGIVER STRATEGIES FOR CONCERNS ABOUT POSSIBLE SEIZURE ACTIVITY:

- Observe for any signs of involuntary jerking of arms or legs, rigid posturing or stiffening of the body, or loss of consciousness.
- Keep possible seizure activity in mind as the reason for unexplained unwitnessed falls that may be occurring.
- Seek attention from a health care provider with detailed description and discuss whether further testing or consultation is necessary to evaluate for seizure activity.

GAIT INSTABILITY AND FALLS

Gait (walking) and balance changes can occur over time due to a combination of memory loss and physical decline. Memory impairment adversely affects an individual's ability to recognize and navigate his or her environment, to coordinate more complex skills, like climbing stairs or stepping off of a curb, and to be aware of how his or her body moves and occupies space. Many other factors that may occur with aging also impair walking and balance, such as worsening eyesight and hearing, loss of muscle strength, arthritis that causes pain and stiffness, and medications that can cause dizziness or poor balance. Falls can be a devastating and life-changing consequence of the deterioration of walking skills, especially if they result in injury or fracture that causes further physical setbacks.

CAREGIVER STRATEGIES TO HELP WITH GAIT AND BALANCE DIFFICULTIES:

- Offer or provide assistance, if possible, when in unfamiliar areas and on stairs, curbs, over thresholds or uneven terrain.
- Provide adequate lighting.
- Use sturdy, supportive, well-fitting footwear and clothing that fits properly.
- Seek assistance from a health care provider or physical therapist for recommendations about an assistive device (i.e.; a cane or walker) or other strategies to help make walking more safe and steady.
- Keep walkways and living spaces at home well-lit and free of clutter, throw rugs, and other tripping hazards.

PHYSICAL AND COGNITIVE WELLNESS IN ALZHEIMER'S DISEASE

Maintaining good physical, emotional, and cognitive health is a lifelong endeavor for everyone and one that should remain a top priority for individuals with Alzheimer's disease. As dementia progresses, individuals experience increased vulnerability for physical, cognitive, or functional setbacks from even seemingly minor stresses, like a viral illness or a mild infection. Thus, an important aim is to preserve good physical and mental health and to avoid any preventable medical setbacks to the fullest extent possible. Below are some simple recommendations that serve as an important defense against pitfalls that can cause a more serious cascade of physical setbacks.

STRATEGIES TO HELP ENHANCE AND MAXIMIZE PHYSICAL HEALTH AND WELLBEING:

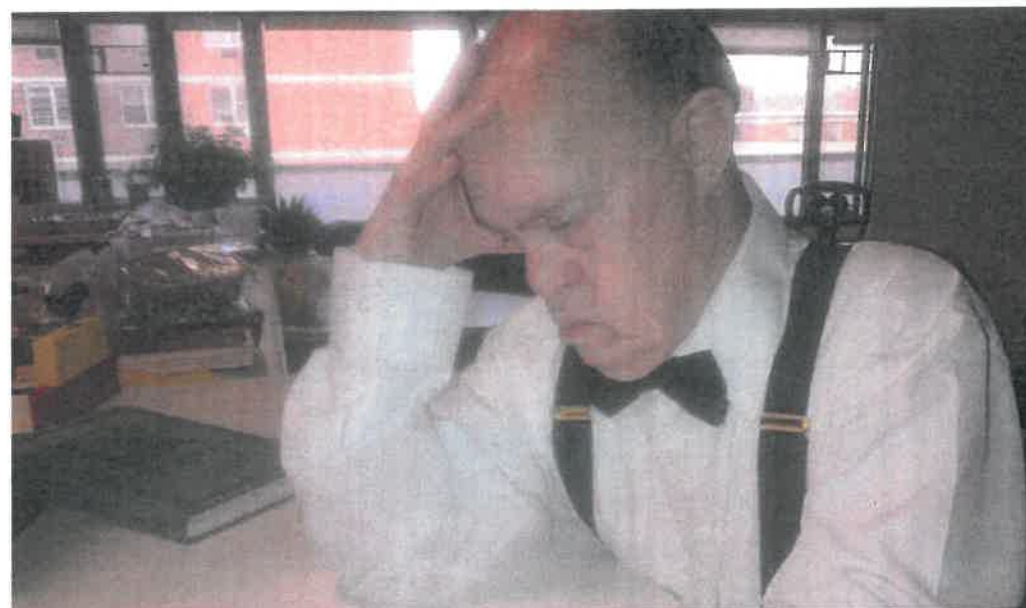
- **Avoid preventable illness** by using good hand hygiene and by avoiding contact with other people who have contagious illnesses like viral infections and common colds
- Ensure the individual keeps up with **regularly recommended vaccinations**
- **Schedule regular checkups** with a health care provider
- Provide **adequate nutrition**, aiming to keep weight in a stable and healthy range
- Provide **adequate hydration** to avoid complications like dehydration or constipation
- Maintain good **daily oral hygiene**
- **Preserve healthy skin integrity and maintain foot care.** Watch for redness, irritation, or breaks in the skin especially in the skin folds and groin. Moisturize dry skin and perform regular skin checks. Bring any new changes to the attention of a health care provider

A NOTE ABOUT SUDDEN CHANGES

The natural progression of Alzheimer's disease is typically a slow and steady decline over time. **Sudden or abrupt decline or rapid acceleration of losses is not consistent with the typical expected course of Alzheimer's disease.** Therefore, any sudden change in mental status or physical functioning should trigger prompt medical attention to look for other root causes that brought on these new changes.

Caregivers are advised to be watchful for any sudden changes rather than the typical gradual losses seen with Alzheimer's disease. Examples of a sudden change may include: an individual with Alzheimer's disease who usually can walk normally but suddenly is unable to stand or walk on his or her own power, or an individual with early stage Alzheimer's disease and only mild forgetfulness who suddenly becomes completely disoriented and confused. Alzheimer's disease alone does not provide the complete explanation for the dramatic changes seen in both of these scenarios, and more investigation would be warranted to look for other causes.

Sudden changes in mental status should be evaluated promptly, as **delirium** (a state of acute confusion) can occur with any number of other physical illnesses. Adults with Alzheimer's disease are at greater risk of developing delirium, and the range of underlying acute causes is broad, including infection, dehydration, medication intolerance, medication side effects, pain, and so on. In delirium, the underlying cause must be identified and treated to help reverse the course of acute confusion. Be vigilant for acute or sudden changes and do not dismiss them as part of underlying dementia. Seek medical guidance or attention for any sudden or unexpected dramatic change in mental or physical functioning.



TREATMENT OF ALZHEIMER'S DISEASE

Dementia treatment revolves largely around the day-to-day care and support provided by caregivers. Unfortunately, currently there is no cure for Alzheimer's disease, and medications are not the cornerstone of treatment. The medications that are used to target the cognitive symptoms of Alzheimer's disease typically provide a modest impact on the individual by treating the symptoms of dementia without impacting the underlying disease process. At their best, they may help slow the progression of the disease, but they do not restore memory or stop further memory loss.

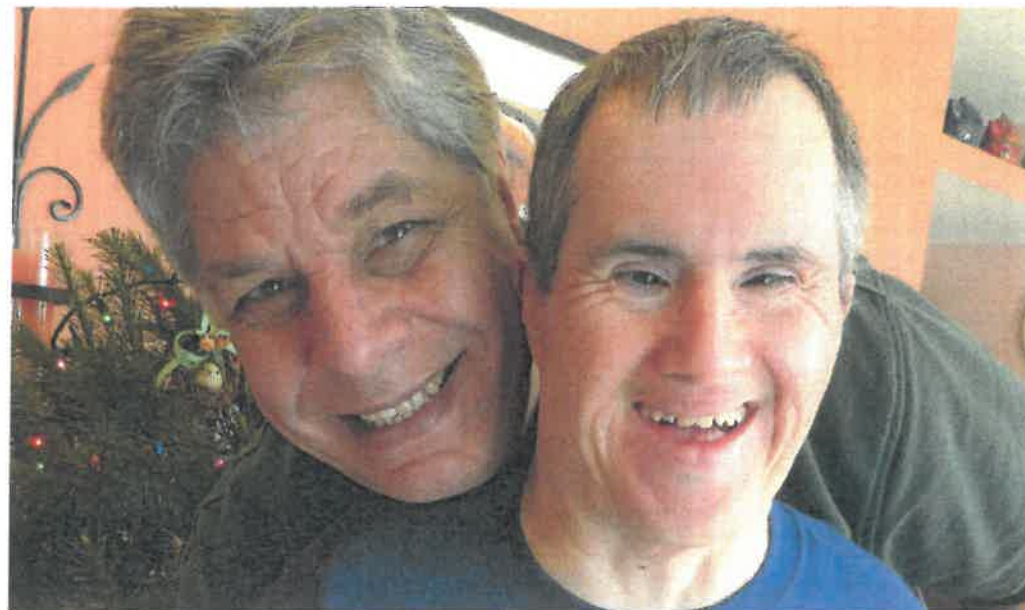
It is beyond the scope of this booklet to discuss available Alzheimer's disease medication treatments in detail, but readers are highly encouraged to discuss this in more depth with a health care provider or seek information from the Alzheimer's Association or similar resource. While medical treatments for Alzheimer's disease are often not dramatic in their impact, medications that address other coexisting conditions do carry great potential for visible results. Treatment of common coexisting conditions that may be identified in adults with Down syndrome may help by relieving pain, disorientation, depression and other discomforts.

A few examples of treatment of coexisting conditions would include:

- Starting thyroid hormone replacement medication if an underactive thyroid is discovered
- Starting an antidepressant medication if the individual is felt to have depression
- Initiating medication to help alleviate pain if arthritis or other pain sources are felt to be contributing to mobility limitations and/or irritability or behavior changes.

GENERAL PRINCIPLES OF CAREGIVING FOR ADULTS WITH ALZHEIMER'S DISEASE

As memory loss progresses, life becomes ever more focused on the present moment. The loss of short term memory makes 10 minutes ago seem like ancient history and the concept of 10 minutes from now too abstract to grasp. If there is a moment to breathe and appreciate it, there is some beauty to be found in being forced to think *only* of right now. By accepting this core fact, caregivers can enter the present here-and-now with the individual and help meet them where they are at that very moment.



Knowing that dementia is a dynamic process, the ability of a caregiver to adapt to change is helpful. Change is one of the guarantees that accompanies an Alzheimer's disease diagnosis. Whatever works today may not be effective six months from now, so stay attuned to the changing needs or patterns of the individual and try to continually reassess what is working and what is not.

Keep in mind that feelings and emotions remain accessible in adults with Alzheimer's disease. Even as memory changes, emotions can provide a good opportunity for connection that supersedes words or logic, and this can be quite a powerful tool to help both the individual and the caregiver feel heard and understood. Alzheimer's disease makes the world more confusing and disorienting, which can stir up feelings of fear, panic, and anxiety. Awareness of these key emotions can allow the caregiver to find solutions that defuse those feelings and move towards a feeling of comfort and security.

PRACTICAL PRINCIPLES AND TIPS FOR CAREGIVERS OF ADULTS WITH DOWN SYNDROME AND ALZHEIMER'S DISEASE

- The individual is more than his or her disease.
- Keep the essence of the individual alive in your mind. What is important to him or her? What have been his or her lifelong preferences?
- Educate yourself – learn about dementia, what to expect, and what resources are available to help you.
- Acknowledge and respect feelings – both your own and those of the individual with dementia.
- Tap into emotions to find a connection – they are powerful communicators if used properly. Gestures like a warm smile, a hand to hold, or a reassuring hug, can say everything without saying a word.
- Be kind... to yourself and to the individual.



- Maintain relationships – for the individual with dementia and for yourself. Stay connected with important long-term relationships and friendships. Keep up social connections with family, friends, and peers.
- In general, provide help only to the extent that it is needed. Resist the urge to just take over and do the entire task because it will take less time or would just be easier.
- Allow the individual to preserve and strengthen existing skills and abilities for as long as possible – this helps him or her preserve their dignity.
- When speaking or interacting, try to maintain a positive tone.
- Maintain a structured, predictable, and familiar daily routine. If most days have a familiar rhythm and flow, this will enhance a sense of safety and security and will reduce anxiety.
- Remain engaged in a variety of mentally stimulating, familiar, and pleasurable activities. Choose activities that use an individual's existing strengths and abilities, to maximize a sense of capability and healthy self-esteem.
- Aim to make activities as "failure proof" as possible to avoid frustration and agitation. Good options are familiar activities that require only 1 or 2 basic steps, like folding dish towels, watering plants, or sorting coupons.
- Aim to stay physically active on a daily basis. Taking a walk together is good for everyone involved, and movement can help expend extra energy while helping promote circulation.
- Support healthy engagement in daily life. Adults with dementia gradually lose the ability to initiate action on their own, and boredom can increase anxiety, agitation, and distressing behaviors.
- Allow time and space to grieve for the losses that are experienced.
- Enjoy the present moment, celebrate the small victories, and live for the day.

PLANNING FOR A MEANINGFUL DAY

Given the progressive and ever-changing nature of Alzheimer's disease, caregivers are encouraged to incorporate activities that bring enjoyment, maintain dignity, and foster existing strengths and capabilities. Structure each day around familiar, mentally stimulating, activities to foster a feeling of value, independence, and healthy self-esteem. These activities will shift and simplify over time but should always emphasize enjoyment and minimize frustration which can lead to anger, sadness, or distressing behaviors.

PRACTICAL TIPS IN PLANNING MEANINGFUL ACTIVITIES¹

When planning activities for an individual with dementia, focus on the person, the activity, the approach, and the place.

¹ Adapted from the Alzheimer's Association, www.alz.org

PERSON	<ul style="list-style-type: none"> • Stick with activities that the person has always enjoyed, adapt as needed to match current abilities. • Pay attention to what activities or settings seem to make the person most happy and relaxed. • Be aware of physical problems, such as arthritis or joint stiffness, vision or hearing loss, and adapt or avoid activities where this would pose a problem or limitation. • Provide choice by offering a few options or visual cues.
ACTIVITY	<ul style="list-style-type: none"> • Focus on enjoyment, not achievement. • Encourage activities that fit into daily life - wiping down countertops, emptying the trash, etc. • Look for favorites - especially if certain activities were a routine part of a typical day - i.e., looking at the sports section, having a cup of tea, clipping coupons, listening to music, etc. • Change activities as needed. Be flexible based on changing needs. Reduce distractions. • Consider the time of day. Pay attention to what time of day the individual seems the most relaxed or calm. Timing of certain activities may need to be adapted to different times of the day to be more successful, such as the showering routine. • Adjust activities to the disease stage - as dementia progresses, introduce more repetitive tasks. Be prepared for the individual to eventually take a more passive role in activities. • Recognize that some agitation may occur late in the afternoon and plan some diversionary activities or offer a quiet room.
APPROACH	<ul style="list-style-type: none"> • Offer support, cues, and supervision. • Concentrate on the process, not the result. • Be flexible - don't force an action or response. • Allow more time to complete activities than previously. • Be realistic. Create a mixture of activity and rest. • Break activities into simple steps and focus on one task at a time. • Let the individual feel useful and helpful. • Relax your expectations. • Don't criticize or correct. • Encourage self-expression. • Involve the person through conversation. Talk to the individual about what you're doing. • Try again later. If something isn't working, it may be the wrong time of day or the activity may be too complicated. Try again some other time, or adapt the activity.
PLACE	<ul style="list-style-type: none"> • Make activities safe. • Change your surroundings to encourage activities - have scrapbooks, photo albums, or magazines within reach to help the person reminisce. • Minimize distractions that can frighten or confuse. • Look around your home and see there are features that may disorient or frighten (e.g., shadows, strange images) and increased the lighting or move the features.



Create a fairly predictable daily schedule to help reduce feelings of anxiety and fear. As dementia progresses, daily activities may take much longer and planning for this inevitability can reduce stress for the individual and the caregiver. For example, in late stage dementia, it may take two hours to get dressed and eat breakfast. The routine is always evolving so accommodate adapt to what the individual can handle at the current time.

The Alzheimer's Association outlines an **Example of a Daily Plan** for early- to middle-stages of the disease. Below is an adapted version which can also be revised based on the routines of the individual's current daily plan of activities and as strengths and capabilities change over time.

EXAMPLE OF A DAILY PLAN

MORNING	AFTERNOON	EVENING
<ul style="list-style-type: none"> - Toilet, wash, brush teeth, get dressed - Prepare and eat breakfast - Have tea, make conversation (talk about the weather or the day, using the newspaper or a calendar) - Fold laundry, try a craft project, reminisce over old photos - Take a break, have some quiet time - Do some chores together - Take a walk, play an active game or do an art project 	<ul style="list-style-type: none"> - Prepare and eat lunch, wash dishes - Listen to music, look at magazines or photos, watch TV or a video - Do some gardening, take a walk, visit a friend - Take a short break or nap 	<ul style="list-style-type: none"> - Prepare and eat dinner, clean up the kitchen - Reminisce over dessert, looking at old photos or listening to favorite music - Play a game, watch a movie, give a massage - Wash or take a bath, get ready for bed, incorporate other bedtime routines

Adapted from the Alzheimer's Association
"Creating a Daily Plan", www.alz.org

EXAMPLES OF ACTIVITIES APPROPRIATE FOR ADULTS WITH ALZHEIMER'S DISEASE

Adapted from the Alzheimer's Association
"101 Activities", www.alz.org

CONVERSATION

- Look at old pictures to prompt reminiscing
- Discuss the weather using the newspaper
- Talk about special date events using a calendar
- Read a book
- Discuss magazine pictures/photos

- Make a greeting card
- Cut/tear pictures for collages
- Color pictures
- Make scrapbook
- Make seasonal decorations

ARTS

- Listen to live music at a community concert
- Use musical instruments (e.g., drum, xylophone, shakers)
- Sing favorite song
- Dance
- Make a family poster
- Knead modeling clay
- Finger paint
- Sand paint
- Sponge paint

USEFUL HOUSEHOLD CHORES

- Fold laundry
- Match socks
- Wash silverware
- Wash windows
- Bake cupcakes or cookies
- Cook a favorite food
- Help make a salad
- Make a sandwich
- Make pudding
- Make a pie from a premade shell

- Arrange flowers
- Help water plants
- Clip coupons
- Make lemonade
- Put out birdseed
- Take out the trash

- Visit a favorite outdoor area
- Walk in the mall
- Plant seeds in pots
- Have a picnic
- Sand a wood block

PHYSICAL ACTIVITIES

- Brush hair
- Massage hands with hand cream
- Toss ball or balloon
- Blow bubbles
- Modified bowling
- Lift small weights
- Chair exercises
- Stretching exercises
- Get manicure
- Ride exercise bike
- Feed ducks
- Rake leaves
- Sweep a patio
- Take a walk in the neighborhood or local park

MISCELLANEOUS

- Look through a clothing catalog or other magazines
- Do puzzles
- Play dominoes
- Play checkers
- Take photos
- Sort coins
- Visit a house of worship
- Have coffee, tea, or ice cream together



COMMUNICATION

Communication is both verbal and nonverbal. As Alzheimer's disease progresses, processing and understanding verbal communication gradually becomes more difficult and thus responses may take longer. Caregivers can help by simplifying verbal communication - using shorter sentences and smaller words, and pairing words with a gesture, gentle touch, or pointing to help get the message across more easily.

As verbal skills decline, individuals often rely more heavily on emotional cues, tuning into tone of voice, facial expression, or body language as a means of trying to interpret what is being said. For example, if a caregiver is feeling frustrated or angry and is speaking in a loud voice with a tense facial expression, the individual with Alzheimer's disease may not fully understand the scenario, but may feel a natural instinct to act defensively.

As a general rule, negative tones and negative words like "Stop!", "No!", or "Don't!" are best avoided. The same is true with negative body language or facial expressions. Adapting nonverbal communication to convey a nurturing sense of safety can be quite powerful, especially in times of stress. Keep the vocabulary simple and easy to understand, speak face-to-face at eye level, use short sentences, and use a gentle and relaxed tone of voice.

IMPROVING COMMUNICATION TO IMPROVE CONNECTIONS

In early stage Alzheimer's disease, an individual may have difficulty finding the right word, telling a story, or keeping up with a conversation. Individuals may become less talkative as a result, or may struggle with answering a question. In middle stage Alzheimer's disease, vocabulary will become more limited and the ability to express oneself in words will become more of a struggle. The ability to hear and understand spoken language will be further impacted, which can cause additional frustration. In late stage Alzheimer's disease, communication is significantly affected, as individuals will have little to no verbal expressive abilities and will have very limited ability following even basic verbal instructions. Adapting communication over the course of Alzheimer's disease is important to avoid the feelings that can arise from feeling misunderstood.

The following tips are recommended for more successful communication:

- Include the individual in conversations with others.
- Take time to listen to how the individual is feeling, what he or she is thinking or may need.

- Talk directly to the individual face-to-face, using clear, simple language.
- It's okay to laugh. Sometimes humor lightens the mood and makes communication easier.
- Allow time for response so the individual can think about what he or she wants to say.
- Be patient and supportive, offering comfort and reassurance to encourage the individual to express his or her thoughts or feelings.
- Avoid criticizing or correcting. Instead, listen and try to find the meaning in what is being said.
- Avoid arguing. You will not win an argument with someone with Alzheimer's disease. Let it be.
- Offer instructions or provide cues one step at a time.
- Ask one question at a time.
- Ask yes or no questions rather than open-ended questions. For example: "Would you like waffles for breakfast?" rather than "What do you want for breakfast?"
- Give visual clues. Point, touch, or gesture to help enhance understanding of what is being said.
- More often than not, the emotions being expressed are more important than what is being said. Look for the feelings behind the words and sounds.

LEARNING THE LANGUAGE OF ALZHEIMER'S DISEASE

In many respects, learning to effectively communicate with individuals with Alzheimer's disease can feel like learning a new language. A successful dialogue does largely depend on the caregiver to mold and adapt their language, tone, and message to suit the individual they are talking to. When caregivers "learn the language of dementia" they can anticipate certain barriers and achieve the ultimate shared goal of being heard and understood. The following adaptive strategies can help avoid unnecessary tension or frustration between the caregiver and the individual at times when neither person feels like their needs are being fully understood.

ADAPTIVE STRATEGY: IT'S NOT ANYONE'S FAULT. IT'S A DISEASE.

When accidents happen or frustration arises, caregivers may often revert to communication techniques that feel familiar to parenting – raising his or her voice, expressing disappointment, or repeating a list of certain set rules or expectations. This approach commonly yields the exact opposite of the desired outcome from the individual with Alzheimer's disease, and may increase agitation, irritability, or combativeness. *Remember to avoid correction, use positive body language, and listen and observe closely and respond to the feelings or emotion behind the message.*

ADAPTIVE STRATEGY: STAY IN THE MOMENT

Communication in Alzheimer's disease centers on remaining in the present moment. *As a result, you should expect to repeat yourself, offer reminders multiple times, and hear the same question or the same story over and over.*

The concept of staying in the present moment also applies to problem-solving when challenging times arise. Memory loss and confusion frequently can lead to emotions of fear, anxiety, or anger for individuals affected by Alzheimer's disease. To help alleviate the mounting stress or anxiety that the individual may be experiencing, **positive redirection** can be a very powerful strategy to help address and defuse negative feelings and emotions. *You can try gently distracting or redirecting the individual towards a more calming or pleasurable activity as a way of changing focus towards a new positive present moment.*



For example, if an individual is starting to get agitated because he or she is insisting that a sister is coming to visit, rather than verbally correcting them (which will likely only escalate anger or start an argument) try redirecting to another topic or task. i.e.; *"Jimmy, I know you miss your sister. Gosh, the last time she visited you made that special peppermint hot chocolate together. Should we go in the kitchen and see if we still have some? Come with me and we'll see!"*

ADAPTIVE STRATEGY: MAKE SIMPLE REQUESTS.

Bargaining and incentives are common strategies used by many people throughout their lifetime to encourage or reward positive behavior, many times with good success. However, for caregivers of adults with Alzheimer's disease, this strategy is no longer useful or practical. For example, if a caregiver said the following: *"Laura, I'm not going to pick up this mess that you made. Please make your bed and put your art supplies away. If you keep things nice and tidy all day I'll take you swimming tonight."* In this scenario, the promise of a future reward is a concept that requires intact short term memory, which is impaired in individuals with Alzheimer's disease. Using this approach will not be effective in adults with dementia.

Behavior strategies that are designed around future rewards based on current behavior are destined to be a struggle, since this plan requires a working memory. Instead, behavior approaches should be adapted to meet the needs of the individual in the present moment. Effective strategies are those that primarily reinforce a sense of calm, reassurance, safety, and security. You can stay in the present moment, and attempt to positively redirect and negative behavior, and listen and respond to the emotion that the individual is expressing.

BASIC BEHAVIORAL PRINCIPLES

Behavior is a form of communication. As Alzheimer's disease progresses and language skills deteriorate, individuals who previously were very expressive may respond behaviorally rather than struggling with verbally expressing his or her basic needs and wants. In this scenario, one's behavior may become the key form of communication, as vocabulary becomes smaller or abilities to find words and make sentences gets more difficult. For example, an individual who could articulate his or her feelings may say: *"I'm upset. It's not fair that Jenny got to go food shopping with you and I had to stay home!"* However, an individual with dementia may just say *"Hey!"* and ball up their fist and hit Jenny.

Behaviors can ebb and flow and can take various forms - physical aggression, verbal aggression, yelling, vocalizing, combativeness with care, delusional thinking, cursing, paranoia, wandering, self-injury, and so on. For some individuals, old behaviors may re-emerge with Alzheimer's disease, and for others new behaviors may arise which may be surprising and out of character for the way the individual had always acted.

It is beyond the scope of this booklet to address every type of behavior that may be seen throughout the lifespan of dementia. Instead, this booklet emphasizes the common themes of behavior, particularly the concept of behavior as communication. The goal then is to try to understand what it is that the individual is trying to communicate through his or her actions. Problem-solving around behavior often feels like detective work - trying to find patterns, identify triggers, or look for other physical or environmental contributors. From there, the process is typically trial-and-error; attempting an approach to improve or modify the behavior and then observing for the response. This strategy is applied throughout the entire course of dementia, since the features of Alzheimer's disease are always changing and therefore the response to behaviors will have to adapt and change over time too.

The following **three-step approach** can help identify common dementia-related behaviors and their causes.

1. Examine the behavior

- What was the behavior? Was it harmful?
- Did something trigger it? What happened immediately after?
- Could something be causing the individual pain?
- Could this be related to medications or illness?

2. Explore potential solutions

- Are the individual's needs being met?
- Can adapting the surroundings comfort the individual?
- Can I change my own reaction or approach?

3. Try different responses

- Did my new response help?
- Do I need to explore other potential causes and solutions? If so, what can I do differently?

COMMON CAUSES OR CONTRIBUTORS TO NEGATIVE BEHAVIORS:

- **Physical pain or discomfort:** illness, medication effects, hunger or thirst
- **Overstimulation:** loud noises or a busy environment
- **Unfamiliar surroundings:** new places or the inability to recognize home
- **Complicated tasks:** frustration stemming from difficulty with activities and chores

*Adapted from the Alzheimer's Association "Behaviors",
www.alz.org*

- **Frustrating interactions:** inability to communicate effectively may cause fear, sadness, or anxiety

- **Personal upheaval:** family illness or poor health in a housemate, grieving over the death of a loved one, loss of a key staff member

- **Boredom:** due to declining ability to occupy unstructured time or to plan or initiate activities. Individuals with dementia become dependent on those around them to help keep them engaged. Boredom can be a major cause of behavioral issues.

A WORD ABOUT PAIN

Pain can frequently be an overlooked key contributor to negative behavior, poor sleep, or agitation. Because pain is subjective and thus dependent on the individual's personal experience and perception of discomfort, recognition of pain symptoms can be missed by caregivers and healthcare providers.

Many individuals with Down syndrome have different ways of expressing pain throughout their lifetime. When Alzheimer's disease is present, the expression of pain can be muddled even further. It is not practical to only rely on self-report of pain, since many individuals will not have the means to express their pain symptoms specifically - i.e.: *"the back of my right knee is really throbbing!"* Instead, look carefully for nonverbal clues of pain or discomfort or to look for any signs of potential pain sources when providing care to the individual. Reviewing the individual's lifelong tendencies around pain reporting can be helpful. Gather information from family about typical facial clues or sounds that have typically correlated with pain symptoms in the past.

Stay mindful of the possibility of pain as a contributing factor when behavior, mobility, or overall demeanor changes. Recall the common conditions that occur with age in adults with Down syndrome: such as osteoporosis and osteoarthritis. These conditions, coupled with increased immobility or risk of skin breakdown or irritation, all raise risk for discomfort or pain. Thus, caregivers and health care providers can together maintain a high suspicion for pain and to look for further evidence of pain symptoms or sources so that this important and treatable factor can be properly addressed.

TYING IT ALL TOGETHER: COMMUNICATION AND BEHAVIORAL STRATEGIES

Incorporating certain core principles and ideas into the overall care of an individual with Alzheimer's disease will help point caregivers in the right direction when trying to problem solve around their own specific challenging scenario.

Key strategies for success with communication and behavior challenges:

- **Validate feelings, empathize.** Remember that actions are often borne out of fear, so reinforce reassuring statements such as *"I'm here to help you", "You're safe"*.
- **Stay in the present moment** when interacting with individuals with Alzheimer's disease. The present moment is all you have.
- Anticipate certain stressful events or times of day and plan accordingly to **minimize anxiety**.
- Try to **tie a pleasurable or distracting activity to a stressful or unpleasant activity** to make it more manageable. For example: put on headphones and play favorite music when cutting toenails, sing songs while giving a bath, bring a soft blanket or other comfort object on the van ride home from the day program.
- **Do not attempt to reason or rationalize.** You will not win an argument with someone with Alzheimer's disease.
- **Stay engaged in pleasurable activities.** Individuals will depend more on the guidance and supervision of caregivers to keep busy.
- Get familiar with the "art" of **positive redirection**. Practice shifting focus and redirecting at times of stress or escalating behavior.

CARE FOR THE CAREGIVER

The word "caregiver" encompasses a very diverse group: aging parents, siblings, extended family members, friends, volunteers, paid professional or lay staff, or other individuals in a committed relationship with the individual.

Parents are often lifelong caregivers, but when a son or daughter is diagnosed with Alzheimer's disease the caregiving role can expand dramatically. This often occurs at a time when parents may be facing their own age-related changes and challenges. Due to the all-encompassing role they play as caregivers over the years, many aging parents may have had fewer opportunities to create and nurture ongoing support through friends



and community. With an Alzheimer's disease diagnosis, when extensive supports are critically needed, families may find themselves unfamiliar with the network of systems or supports in their communities, which can be challenging and stressful.

With the steady increase in life expectancy among adults with Down syndrome, caregiving responsibilities now commonly shift from one generation to the next. Today, siblings very often find themselves moving into a hands-on caregiving role, sometimes also assuming care for an aging parent at the same time. Stepping into a primary caregiving role in the family while trying to balance his or her family and work responsibilities can be overwhelming for siblings, whether they live locally or are attempting to coordinate care from a distance away.

Paid caregivers, such as community services/support staff, may encounter a different variety of challenges. Alzheimer's disease impedes an individual's ability to learn new names and faces, which can mean that even staff who work on a daily basis with an individual may always be regarded as a stranger or may struggle with building trust and developing a rapport. However, working with individuals with Alzheimer's disease can become more intuitive after learning an individual's quirks, typical patterns, and preferences.

There can be great variability across community residential settings and among providers in terms of level of experience and familiarity with serving individuals with Alzheimer's disease. Some may have received formal or informal training on dementia, while others may have no required training at all. Education is empowerment. In this situation, as a general understanding of Alzheimer's disease can help make working with individuals with dementia feel far more satisfying and rewarding.

Across all settings, caregiving is hard work. It can be a deeply loving, gratifying, and meaningful experience, while also at times being stressful, unpredictable, and mentally and physically depleting. The very nature of Alzheimer's disease, with its incremental and progressive decline, implies that caregiving takes stamina. This process is a marathon, not a sprint. For that reason, it is critical that caregivers find ways to replenish themselves, physically, mentally, socially, emotionally and spiritually.

Taking time for oneself can help reduce stress and allow caregivers to reconnect with who they are and what they need as human beings, so they can return to a role that so often asks/requires them to put their own needs aside.

Replenishment can be accomplished by:

- **Practicing good self-care.** Maintain a healthy diet, get plenty of rest and stay hydrated. See a health care provider for routine visits. Be open about the level of stress experienced.
- **Staying active.** The work of a caregiver can be quite physically taxing, but keep in mind that regular, dedicated physical exercise is excellent for reducing stress, promoting healthy sleep, and maintaining overall wellness. Whether by taking a brisk walk, going swimming, or taking a yoga class – finding an exercise routine that feels good and fits into a typical daily schedule will help increase the chances of sticking with it.
- **Staying mentally stimulated.** Caregivers are encouraged to take time to do something that is mentally engaging – reading the newspaper or a good book, doing a puzzle or a word game with friends.
- **Remaining socially engaged.** As a caregiver, it's often hard to find enough time in a day. However, it is important to stay connected to friends and family and to activities that you love. Even if it's only 30 minutes at a time, make time for friends and family and aim to do something fun or relaxing.

Strive to find joy in the little things.

- **Creating a support network.** Seek help and support from friends, family, volunteers, local organizations, religious groups, support groups, and paid staff. Reach out to other caregivers for support, encouragement, and ideas. It helps to know you are not alone.
- **Being kind to yourself.** Acknowledge and accept that you won't be able to do it all. Allow yourself to be imperfect in this process. Maintaining a kindness towards oneself helps caregivers access the kindness and compassion needed for the individual with Alzheimer's disease that her or she cares for.

CAREGIVER STRESS

Ideally, caregivers would find space and time to practice all of the self-care steps listed above on a regular basis. This is a worthy goal to aim for. However, sometimes caregiving responsibilities can be all-consuming, and achieving even one of these self-care goals seems impossible. As time goes on, the caregiver and the individual with Alzheimer's disease function more and more as a dynamic, interrelated partnership. The health and vitality of that partnership depends on the health and wellbeing of both the caregiver and of the individual.

Sometimes the stress of day-in and day-out caregiving is overwhelming and can lead to more serious symptoms of depression or burn-out. Symptoms of anger or irritability, anxiety, sadness, poor concentration, withdrawal from friends/family/activities, poor sleep, and worsened personal health may indicate that the stress of caregiving is having a negative impact on a caregiver's emotional and physical wellbeing. Caregivers should be mindful of the symptoms of stress or burnout, and pay attention to the feedback or observations that may be offered from trusted family and friends. Don't hesitate to reach out for help or talk to your health care provider or other trusted professional if the stress is overwhelming.

Caregiving is not something that can be done all alone. As Alzheimer's disease is always changing and progressing, it is important to recruit a support system early into the process so that there are people and resources to reach out to as the needs eventually arise.

The general goal in Alzheimer's disease caregiving is to stay at least a few steps ahead of the disease itself so that the caregiver and the caregiving environment can rise up to meet the needs as they come. This takes proactive planning, but this is critically important to avoid having to scramble to find help or additional resources in the setting of a crisis.



PRACTICAL NEEDS OVER THE LIFESPAN

There is no crystal ball that helps predict the future clearly for adults with Alzheimer's disease. However, the time course and progression of dementia is also not a totally unknowable abyss. There is a typical progression of the features of Alzheimer's disease as well as certain crossroads that individuals commonly encounter that can be anticipated and prepared for in advance.

Caregivers are encouraged to think proactively about the future, starting with assessing the individual's current needs, the caregiving arrangement, and the current living environment. Taking these factors into account, consider what needs or concerns one might anticipate arising as memory and personal care skills decline.

For example, an individual living at home with his or her aging mother in a 2-story family home has unique and separate care-planning concerns compared to an individual who was living independently in a supported apartment at the time of his or her Alzheimer's disease diagnosis. It is important to start a dialogue early and often about the individual's caregiving needs and the needs of the caregiver, as this will change over time.

As a caregiver, examples of questions to consider include:

- How is the current caregiving situation working?
- Are you capable of meeting his or her current needs?
- What struggles or challenges are being encountered currently?

- What personal or physical limitations do you have?
- What might be a limitation for you in the future? As physical needs grow, what limitations do you see in being able to provide assistance in daily care?
- For how long will this current caregiving situation be sustainable or safe?
- Is this living environment suited for aging-in-place? Are there stairs, an old bathtub, a steep driveway, or other environmental barriers or limitations that would pose a practical or a safety concern for the individual and/or you?
- How much are you or the caregiving team prepared to take on?
- What needs and concerns do you have? Personal health issues? Financial constraints? Access to reliable respite care?
- Are you the currently caring for or responsible for other people - children, aging parents, other clients?
- Are you still working full or part time?
- How is my caregiving role affecting my spouse or partner? My children and family?
- Are you willing to accept help in your own home?

With the diagnosis of Alzheimer's disease, eventually tackling some important decisions is inevitable. Some decisions have to be made more immediately, while other decisions may lie in the future. Eventual changes in cognitive and physical functions require a proactive approach that considers:

Housing and living supports needs. This can be a challenging decision that depends on many factors, including the changing care needs of the individual at the different stages of Alzheimer's disease, the situational capabilities of the family or caregiver, current housing/living situation, and care options and resources in the community. A person-centered and relationship-centered approach aims to keep the individual safe and cared for throughout all the stages of disease. In planning ahead, an aging-in-place model aims to provide a living setting that would allow for adaptations over time to accommodate the individual's changing needs, and avoids having to transition to new care environments when

expected changes arise. Despite best efforts, aging in place may not always be possible.

Medical care. Many individuals with Down syndrome may find it challenging enough to find a health care provider with whom they feel understood. A diagnosis of Alzheimer's disease can lend an additional challenge, although most adult health care providers should have at least a basic familiarity with managing patients with dementia. Finding a trusted health care provider is a very important support to help with concerns as they arise throughout the course of the disease and to help plan for the future and end-of-life.

Medical advocacy. It is important that a companion who knows the individual well accompany him or her to medical appointments or to the emergency room to help share history, current concerns, provide an accurate medication list, and to help assist a medical provider in communicating or interacting with the individual so as to enhance the care they receive. Time spent in preparation for appointments will enable the companion to use time wisely and communicate important issues. Aim to plan appointments based on when the individual is usually most alert and calm.

Legal matters. Many families or other designees may not have explored or planned for the legal, financial and health care planning issues that arise later in life. An Alzheimer's disease diagnosis makes these issues even more relevant. Identifying a decision-maker such as a health care proxy or guardian is necessary as dementia progresses. Legal and financial options can vary from state to state so it's important to check local resources proactively. Recording the person's preferences, their likes and dislikes over his or her lifetime can help keep a person-centered approach to overall decision-making across the disease process. Check with your local Alzheimer's Association or similar group for legal and financial resources.

Safety. Alzheimer's disease can be accompanied by other changes that have an impact on the individual's safety and ability to navigate their environment, such as altered depth perception, hearing loss, unsteady gait, risk of seizures, disorientation and confusion. Safety strategies can encompass home safety (such as removing clutter, improving overall lighting, clearing walkways). This can also include an emergency plan for wandering or getting lost, or if there was an unexpected loss of caregiver. Organizations such as the Alzheimer's Association have programs like **Safe Return** that

¹ Additional information at www.alz.org

can be of assistance.¹

Cultural considerations. Embracing cultural diversity is important component of person-centered care, and allows for a richer understanding of an individual's values and beliefs. Awareness, respect, and understanding of cultural diversity must be incorporated into all caregiving considerations. When an individual with Down syndrome and Alzheimer's disease is entering a new living arrangement or meeting a new caregiver, be sure to provide information about cultural practices that he or she maintains or enjoys.

Overall coordination of care. Coordination, collaboration and communication help foster person-centered care. Involving a team of individuals that are knowledgeable in various aspects of care, and who share information and learn from each other, helps ensure continuity and consistency in the coordination of care for the individual.

PLANNING FOR THE FUTURE

Advance care planning consists of proactively expressing and documenting wishes about how to approach future scenarios that may arise. This is a critical component of Alzheimer's disease care and should be incorporated into discussions throughout every stage of dementia after the diagnosis is made. Some people may have already accomplished some aspect of advance care planning even prior to their Alzheimer's disease diagnosis, either by designating a **health care proxy** or a naming a **legal guardian**, something that may have been already addressed during adulthood. If no aspect of future planning has yet been accomplished at the time of the Alzheimer's disease diagnosis, this is important to undertake as soon as possible, making every effort to involve the individual in future planning.

Discussing wishes about end-of-life is difficult for most people. However, tackling these topics proactively, at a moment when there is no crisis or urgency allows time to think, reflect, ask questions, and ultimately arrive at an informed decision. Preparing proactively for these decisions protects individuals and their decision-makers from feeling rushed or blindsided by choices that are expected to likely arise in the setting of dementia.

End-of-life discussions generally encompass the following key considerations pertinent to progressive dementia:

Resuscitation. Resuscitation discussions refer to scenarios in which an individual is having a cardiopulmonary emergency (cardio: heart, and pulmonary: lung). When an individual's breathing stops entirely or when there are severe breathing difficulties, a typical emergency response is to place that individual on a breathing machine called a ventilator.

Similarly, if an individual's heart stops beating or is in a very dangerous heart rhythm, the typical emergency response is to perform chest compressions (CPR) or possibly deliver electric shocks (defibrillation). As dementia progresses, and especially when an individual is approaching late-stage dementia, decision-makers may outline overall goals of care that may or may not include attempts at resuscitation.

Artificial feeding. These wishes refer to decisions made when an individual's swallowing worsens to the point that he or she is unable to safely swallow food or fluid without risk of choking. Poor nutrition and weight loss may also commonly arise as a consequence of swallowing difficulties, especially as dementia progresses. When an individual's ability to safely eat is at risk, decision-makers are often faced with the option of artificial feeding, usually in the form of a feeding tube, either down the nose or directly into the stomach, to provide a means of nutrition. Risks and potential benefits need to be closely weighed in these situations, especially in cases of late stage dementia taking into consideration the overall goals of care for the individual.

Overall goals of care. A discussion about overall goals should take into consideration preferences, priorities, and overall philosophy about quality of life for the individual as he or she progresses towards late stage Alzheimer's disease. Goals of care discussions often logically lead to further discussion about end-of-life, including a consideration of whether palliative care or hospice care would be desired when late stage disease is present.

It is beyond the scope of this booklet to provide extensive detail about end-of-life decision making, particularly because there are legal issues, terms, rules, and policies that vary from state to state. However, across all scenarios, designation of a health care decision-maker is necessary for an adult with Alzheimer's disease, as dementia will render impossible any complex decision-making, even if the individual did have this capacity prior to their disease. A health care decision-maker is typically a designated health care proxy or a legal guardian. Again, the details of these roles are best left to further discussion with community supports and medical and legal professionals in the individual's local area.



ALZHEIMER'S DISEASE AND END OF LIFE

Alzheimer's disease is characterized by a progressive loss of memory, skills, and abilities, leading eventually to late stage dementia. Death in late stage Alzheimer's disease is typically due to medical complications that arise related to progressive dementia, such as: recurrent infections (from skin/wound or bloodstream infections, aspiration pneumonia, or urinary tract infections), inadequate food or fluid intake, weight loss, or progressive failure to thrive.

Advanced/Late stage Alzheimer's disease has 4 core components, all of which must be present to meet criteria for this stage of disease:

1. **Full functional dependency** - including loss of mobility (either primarily wheelchair or bed-bound), dependency for all personal care (bathing, dressing, toileting), and inability to self-feed
2. **Profound memory impairment** - including inability to recognize close family members or other important caregivers
3. **Loss of meaningful speech** - usually 6 words or fewer, or mainly just vocalizations or sounds
4. **Total incontinence** - including total loss of bowel and bladder function

Late stage dementia does not typically arrive in one pure set of features. For example, some people may show a number of these features but still retain the ability to walk or feed themselves. The natural progression of Alzheimer's disease eventually leads to late stage disease in everyone it affects, provided that they live long enough to manifest all features. Knowing that Alzheimer's disease is terminal, decision-makers may shift overall goals of care in the late stage to primarily emphasizing comfort, preserving dignity and quality of life. Individuals with Alzheimer's disease can qualify to receive palliative care and hospice services to provide additional support to the individual, if this is consistent with the wishes of the health care decision-maker.

Palliative care is a model of care that aims to prioritize the preservation of quality of life by preventing and treating discomfort and suffering. Aspects of palliative care can be offered throughout the continuum of Alzheimer's disease progression, if this is desired by the individual and his or her designated decision-maker. A multidisciplinary palliative care team can help provide input and collaborative physical, emotional and spiritual support, help in symptom management and help in recognizing when referral to hospice care is needed.

Hospice is a service offered by a professional interdisciplinary hospice team and authorized by health care provider to promote comfort, provide symptom management for the patient, and support the family/caregiving team throughout the end of the individual's life and after his or her death. Adults with late stage Alzheimer's disease are eligible for hospice services, which can further support wishes that prioritize preservation of comfort, dignity, and quality of life. Individuals typically eligible for hospice are those who have all features of late stage dementia and who also are starting to exhibit signs of worsening health due to their disease, such as recent infections, weight loss, skin breakdown or ulceration. Palliative care and hospice services are predominantly home-based, and services and supports can be carried out in the individual's own home.

BEREAVEMENT AND GRIEF

For family, caregivers, and loved ones of an individual with Alzheimer's disease, grief and bereavement may often be an emotion that is interwoven into the progression of dementia. To experience Alzheimer's disease is to experience a slow and progressive loss of abilities and skills, which can be bring about feelings of mourning or loss on an ongoing basis. Caregivers are reminded to attend to these feelings and seek support throughout the process to help cope with feelings of grief, to replenish their spirit and to find strength to keep going. It is important to create these resources and supports throughout the span of the disease so that they can be made available for comfort and solace when death occurs.

Bereavement and grief over loss can also be profoundly experienced by people with an intellectual disability and is important to acknowledge and

support housemates, friends, and peers who have been witness to the disease process and all of the visible changes that it may cause. Particularly for housemates or close friends, it is important to provide ample attention to the feelings and emotions that they may be experiencing, knowing that it can be a scary and sad experience that may be difficult to understand. Rituals and other commemoration activities of this individual's life are a part of relationship-centered care and can help console all involved. Validate feelings and allow happy memories or mementos to live on in celebration of the individual's life and the impact of his or her friendship.

AFTERWORD

Reminiscence can be an especially comforting process for family and friends the months and years after the death of a loved one. It is a normal part of the healing process. Enjoying old photos, telling stories, and recalling favorite expressions can bring laughter and joy back into the lives of those who are experiencing loss. The life lost can continue to be celebrated long after an individual's death, and encouraging such rituals can be helpful for all as they seek peace in the special memories they shared.

For friends, peers, and housemates, a time of sharing can bring comfort and allow for the voicing of memories while providing an opportunity to identify any present concerns or lingering questions.

Lifelong caregivers may find the grieving process particularly painful and challenging. Recognition and commemoration of the special relationship shared over a lifetime can be a source of comfort, gratification, and meaning, as the enduring bond of caregiving can span space and time.

The collaborators of this booklet wish to express gratitude to people with Down syndrome, their families, caregivers, and peers for being our greatest teachers. Your shared wisdom and experience forms an important legacy and we sincerely thank you.

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